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How to Promote Self-Determination for Young Children With Disabilities

Evidenced-Based Strategies for Early Childhood Practitioners and Families

Fran Martin, an early interventionist, arrives at the apartment of Jenny, a 3-year-old child with Down's syndrome, to provide services for Jenny and her mom, who is a single parent. Jenny is wearing a pretty pink dress that she chose to wear today. When she enters the family room, Fran is happy to see that the furniture has been rearranged to encourage Jenny's emerging gross motor activity while ensuring her safe use of the space. The toys provided are attractive and interesting to encourage Jenny's activity. Although Jenny has motor movement delays because of a cardiac condition and a number of surgeries to repair her malformed feet, she is beginning to pull up and shift her weight in a standing position. Fran talks with Jenny's mother about both her hopes and her concerns for her daughter. Fran and Jenny's mother continue to discuss ways to provide a safe environment that promotes movement that is both stimulating and interesting.

Imagine that when you woke up this morning, someone had rearranged the furniture, scheduled all your activities, and continued to make every decision for you throughout the day. How might you feel if decisions, such as what you were to wear, when you were to brush your teeth, and what you were to eat for breakfast, were made already for you? These are just some of the basic choices that we make as free and self-reliant adults. In a complex and fast-paced world, adults are faced with numerous decisions on a daily basis. As adults, we need practice and support to make informed choices and decisions to solve simple and complex problems.

A young child with disabilities also needs similar practice and ongoing support to maximize opportunities for learning within the home, in school, and in community settings. The opening vignette with Jenny and her mother, Fran, illustrates how an interventionist and family member can partner to facilitate development of self-determination.

We live in exciting times, where families and practitioners work in close partnership. We have the tools and resources to support young children to grow and learn with the highest of expectations. Young children will one day grow up and need to make countless decisions on their own, as all adults do. Early

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childhood practitioners and families would likely agree that young children should not have free reign over their lives and that they do need specific guidance and boundaries in their daily routines. Children need practice to acquire confidence and competence in making decisions, solving problems, and identifying preferences. These and other abilities directly relate to the concept of self-determination, which is defined as having personal control over one's own life. Self-determination is a basic human right that directly affects one's quality of life (Turnbull & Turnbull, 2001).

There are some issues that frame the underlying premise for this article: How can self-determination in young children best be understood and supported? Mainly, it is important to see that simply growing older does not provide all the needed opportunities to acquire the abilities to make choices and decisions that promote later self-determination. Promoting self-determination is an intentional and ongoing process. The time has come to acknowledge how essential self-determination is in the lives of young children. Parents of young children may not fully understand what self-determination is or what the long-term implications are for their young child. One father of a 4-year-old described this scenario best when he wrote, "Parents need to know what it [self-determination] is, of course. I think they also need to know that it is nothing to be feared; rather it is an opportunity for their son or daughter to live a full life, with proper support" (Palmer, 2004). If practitioners understand that children can acquire

elements of self-determination in their early years, sharing this information with families would be a good first step on the road to self-determination in later years.

Most efforts to understand and support self-determination have dealt solely with adolescents and adults, sometimes overlooking and excluding the foundations in early childhood that are required for successful emergence of self-determination (Doll, Sands, Wehmeyer, & Palmer, 1996). The purpose of this article is to share what is known about early self-determination and to suggest how practitioners can use this information to work in partnership with families to recognize and support the development of self-determination at home. In this article, we provide (a) guiding questions to understand how families think about the concept of self-determination and (b) specific evidence-based strategies to promote self-determination in the home.

Some of the strategies we describe in this article may be appropriate across the entire early childhood period (birth to 8 years old), and some strategies may be more specific to an infant or toddler or to an older child, depending on a variety of interacting variables. These variables include contextual and environmental factors, such as lighting, physical barriers of the home, parent expectations about the future, or reactions to self-determination, as well as child characteristics (e.g., age of child, personality, and type of disability; Erwin & Brown, 2000). We encourage readers to consider these factors when promoting

self-determination in early childhood.

This article is aimed at practitioners working with young children with disabilities, but many strategies listed may also be appropriate for young children without disabilities. Because a wide range of teachers and service providers may work closely with young children with disabilities and their families, we will use the term *practitioners* to refer to all professionals who will likely have opportunities to promote self-determination during the early childhood years. This may include but not be limited to teachers, early interventionists, paraprofessionals, therapists, and psychologists.

What Is Meant by Self-Determination in Early Childhood?

Many discussions about self-determination pertain to adolescents and adults, but the roots of self-determination lie early in life (Erwin & Brown, 2000; Wehmeyer & Palmer, 2000). Consequently, self-determination in the lives of young children has become an important topic of recent discussions (Brotherson, Cook, Erwin, & Weigel, 2008; Erwin & Brown, 2003; Lee, Palmer, Turnbull & Wehmeyer, 2006; Palmer & Wehmeyer, 2003; Shogren & Turnbull, 2006). These discussions describe the significance, unique considerations, and major issues related to self-determination in early childhood. Little of this knowledge base, however, has been made

available to practitioners and families who want and need to have access to current evidence-based information. The research base in early childhood and self-determination continues to grow, and there is much we do know about self-determination.

Self-determination can take many forms, but in general, it involves being able to express preferences and make choices, having a sense of autonomy as an individual, and being able to exert some kind of control over the environment. It is important to keep in mind that providing multiple opportunities and designing responsive environments for choice and decision making are vital. For children who are older, self-determination is essentially about making choices and decisions about one's own life, such as selecting friends and leisure activities, without any more support than necessary. When talking with parents about self-determination and their young children, we need to look to the future. By respecting family wishes and values in concert with meeting child needs and preferences, young children can begin to develop necessary lifelong self-determination skills. Encouraging a supportive social and physical environment in the early years is among the best ways to promote self-determination later in life. Designing environments that encourage and promote active child involvement is also critical.

Together, practitioners and families of young children can provide encouragement for children to learn to self-regulate their own activities (e.g., self-calming, working out simple disagreements); be able

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to make simple choices (e.g., ones that end in either positive or negative outcomes); engage in some supported problem solving; and make a few decisions about toys, playmates, or whether to participate in an activity. Families and practitioners can provide repeated practice and opportunities for choice making, problem solving, and other elements of self-determination that match a child’s interests and capacity. Given the family’s preferences, time, money, and spatial constraints, it is possible to structure the home environment to promote early self-determination including the use of any needed accommodations or specialized equipment.

Furthermore, it is important to consider how to strengthen partnerships with families, especially in regard to recognizing and fostering self-determination of young children in their own homes. Toward that end, the next section offers guidance about how to begin the conversation with families about their personal beliefs and interest in self-determination. Evidence-based strategies are also identified to help support the development of self-determination during the early years in home environments.

Culture and Self-Determination

Families are the primary decision makers for their young children within the context of their values and cultures (Turnbull, Turnbull, Erwin, & Soodak, 2006). Understanding if and how the concept of self-determination is

intertwined with a family’s values and culture is the first step in understanding the support families desire. In addition, considering specific characteristics of the child and home can also affect self-determination. For example, can the child move freely through the home and have ways to communicate needs? Is the family’s home accessible, and is the family able to make physical modifications in the living space (Brotherson et al., 2008)?

Honoring a family’s culture, values, and characteristics begins with open conversations about how the family defines quality of life and then how the concept of self-determination for a child fits within the family’s characteristics and definition of quality of life. Erwin and Brown (2003) have suggested that because “self-determination is personally and culturally determined, it is important to identify with the family the level of importance, if any, that they place on self-determination” (p. 79). Others have suggested that the concept of self-determination reflects more of a Western-society value, and care should be taken to appreciate when aspects of self-determination are in conflict with a family’s value system or definition of quality of life (Kalyanpur & Harry, 1999; Turnbull et al., 2006). For example, some families may value group identity more than individual identity or interdependence more than independence within the family structure. For some families, children are not encouraged to make decisions or choices on their own; some decisions are made by one

Table 1
Questions to Assist Families in Understanding Their Views and Values of Self-Determination in Early Childhood

Consider Family Views and Values About Self-Determination

- What is your family's idea of becoming a successful adult? What skills do adults need to fill the roles they will be expected to play?
- How does your family make decisions? What will your child need to learn to be able to participate in that?
- In what ways does your family support choice making for younger children?
- How do you and others in your family meet the needs of your child when making decisions about how they can best move about (furniture placement, toy arrangements)?
- In general, does your family consider young children to be active learners (e.g., children learn by doing)? Can you tell me more about this?
- How do caregivers of your child encourage choice and freedom of movement?
- Where do you find information and perhaps financial support, if needed, to make adaptations for your child?
- Do you need additional information about making adaptations or about self-determination for your child in the home?

Consider Family Strategies About Self-Determination

- Describe what your child's typical day might look like.
- Describe what an ideal day might look like for your child.
- Tell me about the toys or play materials he or she likes to play with and how he or she gets those toys.
- How does your child move about in your home?
- Where does your child choose to play?
- Does your child have favorite places to be alone? If so, where?
- How does your child tell you what toys, play materials, and activities he or she wants?

family member, or the family might make decisions or choices together.

However, a broader view of the meaning of self-determination suggests that the concept can still have relevance, even in cultures where interdependence is valued more than individual independence. For example, an adult living in an interdependent culture will need to be able to problem solve effectively in social situations to preserve the "face" of the family. The cultural requirement of interdependence does not eliminate the need to make choices in day-to-day living; it only places a different set of criteria on how one chooses (e.g., "How will this choice affect the family?" rather than "How will this choice affect my personal goals?"). In this situation, family members may not agree with the term *self-determination* as a future goal for

their son or daughter, but they might agree that it is important to help their child learn to "make good decisions."

A family's culture and values will shape a child's journey to adulthood (Barrera & Corso, 2002). Practitioners can begin to explore with families some of the questions in Table 1 to understand the views and values that exist in the family. To begin to understand each family's goals for self-determination, it is important that practitioners listen carefully to each family so that they do not make assumptions about what families do or do not want. Practitioners will want to be self-reflective regarding their own beliefs, values, and experiences so that they are aware of the impact their own background may have on what they are hearing from families.

Strategies to Support Self-Determination in the Home

Lisa Harper, an early interventionist, visits the Hernandez home to see Maria, a 6-year-old who has cerebral palsy. The family enjoys being outdoors and supports Maria playing outside with her dog, Bingo. Their home gives the feeling of comfort, and photos of Maria and her drawings are displayed on the walls and refrigerator. The Hernandez family has made a bedroom space off the kitchen for Maria and one of her sisters, eliminating the need to carry Maria up and down the stairs of their two-story home. They have lowered her bed and put her clothes and toys in bins on the floor of her bedroom so that she can choose what she wants to wear and play. With Lisa's support, they have also constructed a child-sized table and supported chair in the living room where she and her siblings can color and draw. Lisa Harper knows that the family values spending time together and values providing Maria choices to participate in family activities.

How can practitioners understand and guide families about the use of strategies to best reflect their values and priorities and those of their children with disabilities? What strategies can practitioners suggest to families? In a study on families and early self-determination in home environments, Brotherson

et al. (2008) identified four categories of self-determination strategies that can be explored with families: (a) engagement with the home environment and others, (b) choice and decision making in the home environment, (c) control and regulation of the home environment, (d) and support of self-esteem in the home environment. The vignette describes how Lisa worked with the Hernandez family to implement strategies in the categories we discuss below. In addition, we provide a description of possible strategies in each of these four categories in Table 2. Within each of these categories, there are questions practitioners can use to support families as they choose which strategies of self-determination reflect their family values, culture, and preferences. Practitioners could use this as a checklist, for example, to identify some strategies that a family would like to implement in the home or identify areas where more resources or information are needed to make modifications.

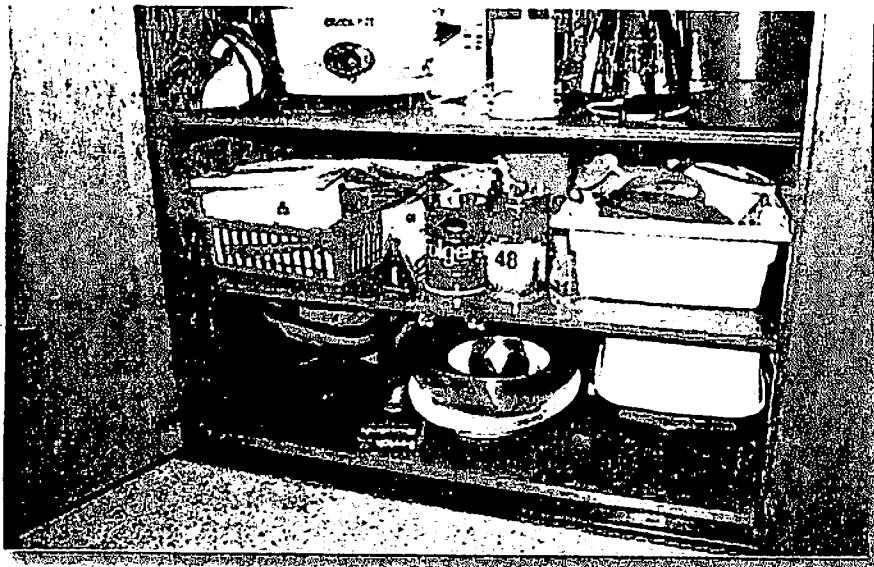
Engagement With the Home and Others

Engagement refers to a child's sustained attention to an activity or an interaction in a positive and an age-appropriate manner (Cook, Brotherson, Weigel, & Erwin, 2007). Skills to relate socially to others begin at home by inviting friends to play and by sharing space and activities with family members. Engagement may be one of the most important ways of nurturing aspects of self-determination. Families can find creative ways to help their children be engaged with their home

Table 2
Strategies for Creating Self-Determination Opportunities in the Home

Category	Strategy	Questions to Ask Families
Engagement with the home and others	Make available play spaces in main living area	<ul style="list-style-type: none"> • Does your child have play spaces in the living/family room? • Are there shelves, baskets, or boxes for playthings in living/family room? • Is there space in the kitchen for play? • Are kitchen drawers or cupboards at child's level? • Are spaces made where your child can leave toys or activities out for short periods of time? • Is it OK to be messy?
	Create spaces for peers to play inside and out	<ul style="list-style-type: none"> • Is there safe outdoor play space and equipment for your child and peers? • Can your child and friends get to indoor and outdoor play spaces? • Can your child reach a variety of playthings by himself or herself? • Can your child put playthings away with or without support? • Are there paved or hard surface play areas for play (i.e., for chalk or wheeled play)?
	Create stimulating spaces to play inside and out	<ul style="list-style-type: none"> • Are there toys or assistive technology equipment that promote play with friends? • Is there a variety of sights, sounds, textures, and aromas available? • Can your child see people, cars, changes in weather, birds, etc., from the windows and doors? • Are there any family pets? • Are there child-sized furnishings provided?
Choice and decision making in the home	Provide accessible play space with access to toys	<ul style="list-style-type: none"> • Do pathways throughout the house allow your child to move with minimal or no assistance? • Are stairways accessible for your child to reach play and living areas? • Are playthings easy to access with minimal or no assistance?
	Present child with options to be independent in dressing and personal care	<ul style="list-style-type: none"> • Does your child have a personal space for clothing? • Are closet and drawers accessible to your child? • Is the bed accessible for your child with minimal or no assistance? • Are there times your child can choose his or her own clothing to wear? • Can your child get to the toothbrush, comb, or bathroom sink with little or no assistance? • Can toilets and tubs be modified to be accessible? • When hungry, is your child able to reach snacks in kitchen?
	Allow the use of adaptive and assistive equipment at home	<ul style="list-style-type: none"> • Is adaptive/assistive equipment accessible to your child, including wheelchairs, communication devices, orthopedic and prosthetic devices, hearing aids, and walkers? • Is adaptive/assistive equipment helpful during family activities, such as meal or other routines? • Are toys, playthings, and household items adapted for your child? • Is there convenient, practical storage space for equipment?
Control and regulation in the home	Support independent movement within or out of home	<ul style="list-style-type: none"> • Are throw rugs removed and flooring clear to support room-to-room access? • Is your child allowed to use adaptive or assistive equipment to facilitate movement? • Does furniture arrangement support easy movement within and between rooms? • Can you remove doorways to support movement?
	Encourage child's self-regulation	<ul style="list-style-type: none"> • Is your child encouraged to move about freely? • Is your child encouraged to express anger or protest? • Is your child encouraged to express a range of emotions? • Does your child have stimulating sights and sounds to explore? • Is your child supported to be involved in learning activities he or she might not do on his or her own (such as reading or looking at books, sorting or matching objects by size or color, or exploring properties of materials, such as sand or water) with supervision? • Is your child encouraged to follow directions that involve several steps? • Is your child supported in voicing his or her emotions or thoughts? (If your child is not quite ready or able to do so, you might say, "It's hard to clean up when you want to play, but we have to eat dinner now.")
	Create personal space for child's privacy	<ul style="list-style-type: none"> • Is your child's bedroom located where he or she can get to it? • Are there areas in the home where your child can safely go to be alone? • Can your child have privacy on the toilet? Does your child have time and place to listen privately to music or be quiet?
Support of self-esteem in the home	Allow child opportunities to control personal space	<ul style="list-style-type: none"> • Is your child allowed to close the bedroom door for privacy? • Can your child regulate lighting and sound in the home? • Does your child have a cubby, tent, or corner he or she controls?
	Provide child with places to see himself or herself	<ul style="list-style-type: none"> • Can your child see himself or herself in a full-length mirror? • Can your child see himself or herself in a mirror while brushing teeth, dressing, or doing other daily activities?
Support of self-esteem in the home	Provide child opportunities to see his or her own work/art displayed	<ul style="list-style-type: none"> • Are family photos displayed at your child's eye level? • Are there displays of your child's artwork in the home? • Are your child's "found treasures" displayed?

Note: Adapted from Brotherson and Cook (2006) and Cook, Brotherson, and Weigel (2004).



environment and with others in the home. They can make stimulating play spaces available in main living areas and create spaces for peers and siblings to play together both inside and outside.

Choice and Decision Making in the Home

Something as simple as turning on a light, getting into or out of bed, or selecting clothes for the day can give young children opportunities to express choice and make decisions. Developing these skills begins early in life in the home environment. Parents can provide these opportunities to their children in a variety of ways. They may offer their children a variety of options to be independent in dressing or personal care, or they may promote the use of assistive equipment in the home to encourage participation in family activities. They also may make physical changes in the home to

support independent movement within and outside of the house.

Control and Regulation in the Home

Children enjoy the freedom to explore their environment and to express their identity through their use of space. Children typically explore kitchen cabinets, turn lights on or off, or close the door when they want privacy. For children with physical or cognitive disabilities, however, families often must play a more active and purposive role in planning opportunities for them to control and regulate the environment. Privacy, for example, is important to consider because it involves setting up and maintaining boundaries between the self and others. Families can explore ways that young children might experience some privacy while balancing it with the issue of safety.

Support of Self-Esteem in the Home Environment

Healthy self-esteem can be an important factor in the development of self-determination (Brotherson et al., 2008). The home plays an important role in a child's development of self. If a child does not know himself or herself, he or she may be less likely to know or value his or her own goals or desires. Positive engagement with family and friends, making choices and decisions independently, and interacting with one's environment are steps to building healthy



self-esteem. Self-esteem is a complex factor that includes responsive social interactions with parents and adults, but it may also include some simple strategies in the home environment. Strategies that families might use to bolster self-confidence and self-esteem could include providing a mirror for a child to see himself or

herself, displaying a child's drawings or found treasures, and displaying photographs of the child in activities with family and friends.

There are barriers that can interfere with the development or facilitation of self-determination during the early years. For example, some strategies will work for some families, and some may not. Some strategies work only some of the time or at the "right time." Children may be in settings where there are limited or no opportunities for choice and simple decision making. In some cases, adults may manage most things for a young child rather than support functional and supportive environments and experiences where children can practice using emerging skills effectively.

It is the job of the practitioner to be attuned to the changing priorities and preferences of families as well as children regarding self-determination. As practitioners, we urge you to take on this challenge of promoting self-determination in early childhood together with families. Discuss it with families, talk about it as a team, and incorporate it into professional development. The support provided for young children and families to encourage self-determination at home can happen only with our urgent commitment to making it possible.

Concluding Thoughts

Let's fast-forward to Jenny's and Maria's families in several years as Jenny and Maria are getting ready to transition from high school to adult services and supports.

Both Jenny and Maria benefited from the supportive environments and encouragement from family and professionals to maximize opportunities and pursue careers and lives that they chose. In short, opportunities for self-determination led to a high quality of life for both young women.



Jenny Foster is discussing with her family and special education teacher whether she wants to work at the child care center at the college campus in their community or at the Head Start program at the elementary school. For a long time, Jenny has enjoyed and gained positive experiences with children through a variety of exciting opportunities, such as in the child care center run by her aunt, in her high school's supported work activities, and also at her church. Having a job working with or near young children has been Jenny's dream, which is quickly becoming a reality. Jenny's mother, the extended family, and the school-based team have supported Jenny to be involved in a number of meaningful school

and community activities. In addition, Jenny has been provided since her early years with as many opportunities as possible to learn through experience how to make informed choices and decisions. Jenny's family is especially pleased because she has learned how to move about in the world safely.

Maria Hernandez has made great progress in the years since she received intervention as a young child. As she gets ready to leave high school and attend a community college nearby, Maria's family is excited for her to be involved in her job at a local veterinarian's office. If everything goes well in her courses, Maria's family has promised to support her transition to the state university in a nearby community to gain

the needed courses so that she can pursue her dream of becoming a veterinarian in the future. All this would not have been possible without obtaining services and support from the local education agency, school district, and the nationally known medical clinic within her state to ameliorate the effects of her cerebral palsy and find support for assisted locomotion. Through the years, Maria gained confidence and autonomy through many opportunities and effective changes in her environment. This could not have been possible without the intentional guided practice leading to Maria's eventual independence as well as expanding her family's and her own hopes for the future.

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