HIDDEN VOICES: PARENTS’ PERSPECTIVES ON THE BARRIERS TO AND FACILITATORS OF INCLUSION ON THEIR PRESCHOOL CHILDREN WITH DISABILITIES

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ABSTRACT

The impact of inclusion programs on children goes beyond the classroom. It reflects families’ and children’s experiences with school systems and communities. Inclusion is more than an issue of disability, a set of strategies, or a placement. It involves the need for all children to be a part of the classroom (Odom, Schwartz, & ECRII Investigators, 2002) and for their families to be a part of their educational experiences (Soodak & Erwin, 1995). The purpose of this chapter is to identify the barriers to and facilitators of inclusion in early childhood programs through listening to the voices of parents and analyzing effective inclusive practices in the literature. The chapter is organized around five themes derived from the voices of parents about their children with disabilities in preschool placements. These themes are then connected to the findings in...
the literature including the key characteristics of early childhood inclusion programs. The reader is encouraged to identify the barriers to and facilitators of inclusion that the parents share through their lived experiences for each theme as well as reflect on the ways in which schools can include and collaborate with parents to foster a partnership that supports all children.

**Keywords:** Inclusion programs; preschool; early childhood; disabilities; lived experiences; reflections

Almost 750,000 children ages 3–5 in the United States received disability services during the 2013–2014 school year under the Individuals with Disabilities Education Act (Office of Special Education and Rehabilitative Services [OSERS], 2015). While this number represents more than 6% of all children this age, most of the data about these preschoolers and the services they receive is derived from standard assessments or information provided by educators. There is limited research on parents’ perspectives about the services their young children with disabilities receive and the way in which the parents and their children are included in the preschool experience (Soodak & Erwin, 2000).

**DISABILITIES AND SERVICES FOR PRESCHOOL CHILDREN**

The most prevalent disability category for 3–5-year-old children in 2013–2014 was speech or language impairments (44.2%) which was followed by developmental delay (37.1%), autism (8.4%), and other disabilities combined (10.3%). Approximately, 66% of these preschoolers had at least some participation in a *regular early childhood program* (defined by OSERS as a program that is offered to *all* children, with or without disabilities, at a public or private school), yet only 38% of this group attended such a program at least 10 hours per week. The majority of preschoolers receiving disability services were minimally included (or not at all) in a *regular early childhood program*. They, instead, received their services at a separate school,
residential facility, home, or service provider location with limited or no opportunity to interact with their peers without disabilities (OSERS, 2015). These varied services and degrees of inclusion provided for preschoolers with disabilities can greatly impact the children served as well as their families (Odom, 2000; Odom, Buysse, & Soukakou, 2011; Odom et al., 2004).

THE IMPACT AND KEY CHARACTERISTICS OF INCLUSION PROGRAMS

The impact of inclusion programs on children goes beyond the classroom. It reflects families' and children's experiences with school systems and communities. Inclusion is more than an issue of disability, a set of strategies, or a placement. It involves the need for all children to be a part of the classroom (Odom, Schwartz, & ECRII Investigators, 2002) and for their families to be a part of their educational experiences (Soodak & Erwin, 1995). “Inclusion is about belonging to a community — a group of friends, a school community, or a neighborhood” (Allen & Schwartz, 2001, p. 2). The degree to which an inclusion program creates a sense of belonging for the students and their families and ultimately supports the success of its children is dependent on its unique characteristics (Schwartz, Sandall, Odom, Horn, & Beckman, 2002).

There are four key characteristics of early childhood inclusion programs identified in the literature: Program Philosophy, Scheduling, Curriculum, and Adult Issues. Program Philosophy is about how the organization values inclusion and how much the value is reflected in all facets of the educational experience and at all levels. It includes the importance placed on family beliefs, culture, choice, and involvement as well as decisions about the proportion of children with disabilities to their peers without. Scheduling comprises various aspects of enrollment, such as the amount of time that the groups of children (with and without disabilities) are together. The quality of and accessibility to the Curriculum includes appropriate adaptations, modifications, and other means of supporting and engaging all children as well as opportunities for peer interaction. Adult Issues are comprised of training, staffing, involving families, and collaborating as a team. While there is no prescribed ideal model, it is the way in which a preschool develops its program in these four areas that results in strengths and successes for the children, families, and staff (Schwartz et al., 2002).
Inclusive models at the preschool level have been studied throughout the past four decades by educational researchers for their benefits (Odom et al., 2002); however, there is limited research that includes parents’ voices about their children’s experiences and how inclusive programs and practices impact families and school communities (Soodak & Erwin, 2000). The purpose of this chapter is to identify the barriers to and facilitators of inclusion in early childhood programs through listening to the voices of parents and analyzing effective inclusive practices in the literature. The chapter is organized around five themes derived from (a) the voice of a parent who shares the barriers she faced as she navigated the educational system with the three of her five children who were diagnosed with multiple disabilities at the preschool level, and (b) the perspectives of 14 parents of children with disabilities who participated in a longitudinal research study and identified the facilitators of successful inclusion for all children in a full-inclusion preschool program (Warren, 2015; Warren, Martinez, & Sortino, 2012). These themes are then connected to the findings in the literature including the key characteristics of early childhood inclusion programs.

KEY LEARNING POINTS OF THE CHAPTER

This chapter will support readers in:

- understanding characteristics of effective inclusion programs at the preschool level regarding academic, social, and emotional domains
- identifying barriers to inclusion for preschool children with disabilities and their families
- identifying facilitators of effective inclusion for preschool children with disabilities and their families
- understanding the theoretical perspectives related to effective inclusive practices at the preschool level

Each theme includes: (a) the story of the parent (Maria), (b) theoretical underpinnings from the literature related to inclusion at the preschool level, and (c) the voices of the 14 parents about evidence-based strategies for fostering inclusion (see the appendix for a description of the full-inclusion preschool program). The reader is encouraged to identify the barriers to and facilitators of inclusion that the parents share through their lived experiences for each theme as well as reflect on the ways in which schools can include and collaborate with parents to foster a partnership that supports all children. (All names are pseudonyms.)
VALUING PEOPLE AND AN INCLUSIVE CULTURE THROUGHOUT THE PRESCHOOL PROGRAM

Maria

My first experience with my oldest son with disabilities provided a dismal view of the educational system and how it is not really designed to include children with disabilities or their families. As a new parent with a toddler that was challenged with learning and social behaviors, I felt helpless. After his diagnosis of high functioning autism, all I wanted was support so that he could progress successfully in his educational experience and eventually in the real world. Instead I was told that it was best for him to be sent off to a special program which meant he would not participate with regular children (defined by the IEP team as those without disabilities).

My poor, three-year old Juan was bussed for 30 minutes to a county sponsored program in another city far from home. He had no interaction with children without disabilities that could serve as positive role models. The members of the IEP team never asked me, his mother, about our family or my expectations for my son. In fact, it was made clear to me that my job was to listen, accept what was decided for my son, and follow any directions or recommendations made by the team and eventually the school.

Once he began in the segregated preschool program, I was told to read to Juan and that it would be best if I only spoke to him in English. There seemed to be an underlying assumption that I did not read to my child and that only Spanish was spoken in the home. If the teachers or program directors had ever taken the time to get to know me, ask about my child-rearing practices, or visit our home, they would have discovered that their assumptions were very wrong. I read to my children all of the time and promote literacy in many ways. I also know my children’s strengths and areas for growth but, in this and many other future experiences, I was not included in Juan’s educational plan.

It was evident over the next two years of Juan’s segregated preschool experience that there was a belief that students receiving disability services should be separated from the children and adults in the regular school program. This was reflected in the placement, actions, and attitudes at all levels from the instructional aides, to the teachers, to the program directors, to the district administrators. This attitude of separation was not only for the children with disabilities but was similarly true for their parents.

A shared philosophy supporting inclusion is one of the four key characteristics of successful early childhood inclusion programs identified in the
literature (Odom et al., 2002). A common ethos for inclusion involves all members of the school program as well as the families of the children. Hurst and Joseph (1998) argue for sharing education or the collaboration of parents and educators in support of children’s living and learning. This joining of worlds requires deep understandings of the cultural differences between home and school as well as a commitment to the shared experiences that can bring opportunities for student and adult growth (Link, 2015; Soodak & Erwin, 2000). At the heart of this is a school culture that not only values inclusion, but also the home and what parents can contribute.

Schools where children and their families are valued focus on building relationships. Educators in successful, inclusive preschool programs understand that by building relationships with the children’s parents, providing them with resources such as training, and including them as active partners and decision-makers in the preschool program, the children will gain even more support and success (Epstein, 2009).

Relationships and participation are about building a new pedagogical space that is always striving toward an education that is the best for children; but it is also much more than this because it represents a process of understanding life, and within life, education. (Balauer, 2004, p. 32)

Collaborating with families requires a process-oriented approach that is focused on relationship-building. It evolves like a friendship with conversation and mutual self-disclosure; avoids formal measures; and is nonjudgmental, supportive, and caring (Summers et al., 1990). When parents feel valued by school staff and a sense of belonging at their children’s school, their self-efficacy increases along with their self-worth (Suzuki, Holloway, Yamamoto, & Mindnich, 2009).

Valuing parents includes respect for the family’s culture and beliefs, particularly related to child-rearing practices and education. Schools where staff take the time to learn about the children’s backgrounds and home lives are better able to collaborate with parents (Kalyanpur, Harry, & Skrtic, 2000). Understanding cultural differences and respecting them is critical in building positive home-school relationships as well as understanding one’s own assumptions and biases about diversity (Kalyanpur & Harry, 1997). For example, research indicates that Latino parents often do not have frequent contact with schools or challenge decisions made by educators due to a cultural respect for teachers. This is often misinterpreted by schools as an indication that the parents do not care about their child’s education (Keyser, 2001; Lian & Fontanez-Phelan, 2001; Sheldon, 2002).
According to Kalyanpur and Harry, educators need to engage in cultural reciprocity with parents through discussions of cultural values and practice and then respect the differences as they respond to families’ needs. Making an effort to understand and appreciate parents’ intentions strengthens the bond between home and school and fosters a strong collaborative relationship.

*Step-Up Full-Inclusion Preschool Parents*

Parents in the Step-up full-inclusion preschool program recognize that the preschool program’s culture reflects a strong belief in children and the value of full-inclusion by all members and at all levels. They perceive that there is an ethos of inclusion at the very heart of the work being undertaken by everyone. Parents acknowledge the benefit of the program recruiting and training a team of preschool staff who share the same positive philosophy about full-inclusion: teachers, instructional aides, specialists, and administrators. The focus is clearly always on children with every effort made to support their success. Parents recognize that the staff all hold the belief that by having children with disabilities learning alongside of their non-disabled peers, everyone benefits.

There is a commitment at all levels of the program to build relationships with the children’s families which begins at the first meeting. The program director and specialists (school psychologist, nurse, speech/language specialist, and occupational therapist) along with the teachers and instructional aides take time to talk with parents at the initial meeting and regularly throughout the program. They value the input parents can provide about their child: background information on the child and family, updates or progress on academic and social behaviors at home, and parental goals for their children. Parents are also routinely included in school activities such as a school garden, parent training on school curriculum and positive instructional strategies to use with children to enhance their academic and social learning, and theme days where the children participate in special experiences around a topic. The parents are not only asked to physically participate or provide information about their children, but also they are included in many aspects of the decision-making of the program including providing ongoing feedback about all features of Step-up. This level of inclusion, in the decision-making, is seldom a part of educational organizations but, according to Epstein (2009), is the hallmark of a commitment to true family engagement. “Staff genuinely focus on each child’s success and include parents in the process” (parent comment).
The shared inclusive philosophy inherent in all aspects of the Step-up program is aligned with the families’ goals of having their children be a part of a general classroom and eventually successfully integrated into and participating in society. Parents express relief that there is a sense of belonging for their children and for them. One way this is noted is in how staff treat all of the children like they are part of this special family and know all of the children and their family members in the program by name, not only those in their own classrooms. “The children in the program are not seen as a problem to be solved but a flower to be watered” (parent comment).

**EXPECTATIONS FOR ACADEMIC AND SOCIAL GROWTH**

*Maria*

Most parents, regardless if their child has a special need or not, want their child to be on track academically. We invest time in teaching our children, we read to them, and we buy toys that will ignite their imagination and fill them with curiosity, all with one goal and that is that they have an academic advantage when they enter school. We want our children to be academically on target, we expect that the school and teacher have the same goal, however, that is not always the case. When you have a child with special needs, unfortunately, the academic part seems to take the back seat at school with a focus on behavior. It’s as if you have to “choose” whether you want your child to learn or you want your child’s needs met. Too many times the school cannot seem to be able to provide both and too many times they can’t provide either.

With Juan appropriate accommodations were not provided nor academic goals met in preschool. He was simply there. He didn’t have to learn anything. As long as he could do the basics he was passed to the next grade. Even now all the academic motivation comes from us, the parents, not the school. The school really doesn’t do anything unless a child falls behind two grades. So children are often content with doing the bare minimum.

With Adan, our youngest son, the experience was quite different. He was finally allowed to join a full-inclusion preschool program (After experiencing the consequences of Juan from a misplacement that began in preschool, I refused to sign Adan’s IEP until he was provided the appropriate services). The special education teacher and I sat down and went over his academic strengths and weaknesses. She was just as excited as me to watch Adan grow
and bloom not only working on autistic behavior issues but his academic growth, although he was already ahead for his grade and age. Adan went into preschool knowing all of the basic kinder skills and he left reading at a 1st grade level and doing simple addition. The difference between one child and the other is like night and day. Adan knows he is smart because his teachers have made it very clear. He often says, “Momma I am very clever you know,” and he is. I like to think that I helped a lot with that but I know that without the proper support and high expectations from his preschool, it would not have been the same. My expectations were high for Adan. The school, after listening to me, was able to place him in a setting that challenged him so he could meet those goals.

Inclusion is an educational goal held by parents for their young children with disabilities (Hanline & Halvorsen, 1989). Inclusion is not an alternative to raising achievement but rather they are coterminous poles of the mission of social justice (Ainscow, Booth, & Dyson, 2004). Parents of children with disabilities want them to become a member of the class and eventually a member of the world (Odom et al., 2002), yet the path for this to occur is often unclear or obstructed (Gershwin Mueller, Milian, & Islas Lopez, 2009). Scorgie (2015) in her study of parent perspectives on school membership found that parents, “treasured teachers whose creativity and openness to accommodations allowed their children to experience belonging and achievement” (p. 48). Parents want the school to understand the expectations for academic and social growth that they hold for their children and desire to collaborate with the educators as they all work toward the shared goals.

Meeting parents’ expectations for their children’s academic and social growth involves issues related to scheduling, such as the amount of time the child is included, and curriculum. These are two of the key aspects of early childhood programs that when developed well can result in strengths and successes for the children, families, and staff (Odom et al., 2002). It is essential that inclusive preschool programs place an emphasis on language development since the disability category with the highest numbers for preschoolers (44.2%) is speech or language impairments (OSERS, 2015). Research affirms the importance of a strong instructional literacy component in inclusive preschool special education classrooms (Guo, Sawyer, Justice, & Kaderavek, 2013).

Odom et al. (2006) highlight the critical importance of educators promoting social competence and acceptance of children with disabilities in inclusive preschool environments. Social integration must be intentional
with the teachers in the classrooms and inherent in the program’s philosophy and goals (Odom, 2000). Furthermore, Soukakou (2012) identifies two fundamental guiding principles for early childhood education related to social development. Preschool classrooms must include “a sense of membership, positive social relationships, and friendships” (p. 480) and adult-child social interactions that positively promote development.

Step-Up Full-Inclusion Preschool Parents

Some parents in the Step-up Program reported initially not knowing what to expect from a full-inclusion preschool program. Others admitted having high expectations that their children would make significant gains academically and socially, despite their delays and disabilities. Two parents said that they wanted their children to love school. One parent talked about wanting her child with disabilities to get the attention he needed and for the other children to raise him up and challenge him. Overwhelmingly, the parents shared their satisfaction in that the full-inclusion program not only met their expectations but also exceeded them.

Parents in Step-up believe that the full-inclusion program has met or exceeded their expectations. They each want their children to grow and be successful academically and socially. This includes opportunities for their children to be with non-disabled peers for their entire preschool day as well as to participate in a curriculum experience that is engaging and appropriate with adaptations, modifications, and other support. Parents all acknowledge significant academic growth in students as a result of the full-inclusion preschool program. They attribute the growth to the characteristics of the program including: a goal-oriented focus; a high-quality, engaging curriculum that prepares the children for kindergarten; a strong emphasis on language acquisition and literacy with a speech/language specialist on the team for all children; learning through play; the integration of thinking skills; modifications and differentiation in the curriculum to meet individual needs; ongoing monitoring of students’ progress aligned with preschool standards and students’ IEP goals; and high expectations for all. Parents also share many examples of the ways in which the full-inclusion program helps students, particularly their children with disabilities, learn how to socialize. They believe that the social transformation of the children is a result of the inclusion model in which children are encouraged to accept individual differences and children with disabilities are provided peers and adults who model acceptable behavior.
COMMUNICATION AND COLLABORATION AMONG ALL GROUPS

Maria

As the mother of more than one special needs child I am faced with many challenges, however none more difficult, confusing, and lonely as facing the school district. I want to help my children and believe this is what the school wants as well, but then I promptly realize it’s not that easy. There are rules, regulations, and guidelines that I am given a copy of at every meeting. Yet they are written in another language, one I don’t understand and the school does not bother to translate for me. If a child's disability is obvious, things may be easier, but when my child has an invisible disability such as high functioning autism I am either going to accept what is or isn't offered to him or I must learn to fight. There is no negotiating or asking me about what I believe is best for my child. It is the school’s way or no way at all. This journey has been difficult and I wish that educators would communicate and work with me for the success of my children.

Soukakou (2012) highlights the importance of inter-related systems of practice that are at the heart of high-quality inclusion programs. All elements of the programs must work together through ongoing communication and collaboration, the cornerstones of effective inclusion programs, to support the students. This includes all levels of the school organization from the district office to the teachers and instructional aides in the classroom as well as the families who know their children best (Lieber et al., 2002; Odom et al., 2002, 2011).

Educators need to ensure that communication with families is clear and inviting. Communication in the area of special education often includes use of a language system comprised of terminology unique to the field (Turnbull, Turnbull, Erwin, & Soodak, 2006). When parents experience this language in formal meetings, particularly regarding assessment and placement of their children, they often feel confused, alone, and distanced from the school (Gershwin Mueller et al., 2009).

Schwartz et al. (2002) identify involving families and collaborating as a team as adult issues or the final key characteristic of inclusive preschools that, when positively implemented, can become a strong point of the program. Hurst and Joseph (1998) emphasize that collaborating and communicating with parents requires a commitment:
Contacts with the home should be seen as a part of the curriculum, and a part of the practitioner’s responsibility to provide for children’s learning in ways that suit them. The first step is to consider what kind of contact with parents is most valuable, and to find out what kind of contact with the setting is needed by the parents. (p. 89)

The benefit of home-school collaboration is that the adults work together to support the children in all aspects of their lives. “If a common purpose is made apparent (that of constructing a better school, society and world for children), then the power of relationships, the absolute necessity for all protagonists to be involved and the value of communication becomes paramount” (Nutbrown, Clough, & Atherton, 2013, p. 132).

**Step-Up Full-Inclusion Preschool Parents**

Collaboration and communication are highlighted by the parents in Step-up as positive elements in the full-inclusion program and important for its success. Frequent collaboration occurs within the school staff at all levels and between the staff and parents. Parents value the multiple levels of communication, both formal and informal, supporting collaboration. They identify the many ways in which the school staff regularly reach out to communicate with and involve families. School staff frequently invite parents to team-up with them in supporting students’ IEP goals and overall success both at school and home. Parents overwhelmingly feel included in the process and well-informed about their children’s progress. Communication occurs through parents’ or guardians’ daily chats with the teachers, instructional aides, and specialists when picking up the children from class; notes and phone calls home; parent trainings and meetings about the program; and scheduled conferences. Communication is not seen as a one-way conversation of school staff telling parents what their children are doing or what the parents should do. Rather it is a two-way conversation exchanging information and ideas to better support the child at school and home. Through the ongoing communication and inclusion in their children’s educational experience, parents’ expectations are heard and valued and the home and school collaborate to reach the educational goals of the children.

Parents in Step-up also recognize the importance of teachers constantly collaborating with each other, the instructional aides, and specialists who work in the program to design the best program overall for each child. This high level of collaboration is made possible through an important structural aspect of the program. The Step-up program is designed to
ensure: (a) all staff are collaboratively involved in continuous program development, (b) there is time allocated for planning and ongoing professional development for the entire staff, including teachers, instructional aides, and specialists all day every Friday (children attend Monday through Thursday), and (c) leadership and support are provided from the district office including a willingness to allow flexibility within the program design. This flexibility includes the ability to, with the consent of the teachers’ union, create a non-standard work day/week for teachers to accommodate the four days of teaching and Friday planning. This non-standard schedule allows the collaboration that fosters the shared vision of inclusion for all.

INCREASING CONFIDENCE FOR SUCCESS IN PRESCHOOL AND IN THE FUTURE

Maria

The biggest challenge for all three of my boys with special needs is social appropriateness. It doesn’t come natural for my boys, for any of them. They are inappropriate many times, they are awkward, and they have no filter and very little common sense. I wish that schools understood just how important the social aspect is for all children but even more so for children with special needs. These kids lack self-esteem because they feel out of place all of the time. Creating a safe social environment for children with special needs is crucial not only for their academic success but for their personal success. They can only grow in a place where they are accepted by children with and without disabilities. Integrated, inclusive preschools offer this to special needs children and it works.

Adan, my youngest, is a very different child than his siblings, largely due to him gaining confidence through being in an inclusion program. He is more verbal, more willing to interact with others, and much more confident in himself. The difference between my middle son and Adan at the same age is enormous. The confidence is not only reflected in Adan’s self-esteem but transfers over to his academics. He is willing to try anything because he is not self-conscious. When you look at Adan you do not see a boy with autism, you see a happy, bright, funny, and charismatic child. How I wish the school had listened to me with my older sons. Perhaps they would not have experienced all of the issues they have now that affect them socially and academically. As a parent of children with special needs, I know that academics and healthy
social interaction go hand in hand and are crucial to a child’s academic success from the first day a child steps into the classroom. Being included has helped Adan and also helped me.

Increasing Children’s Confidence

Preschool children with disabilities often enter an educational program with little exposure to individuals outside of their family. Since 44% of them are diagnosed with speech or language impairments (OSERS, 2015), their ability to communicate can be limited. These and other limitations related to their disabilities, coupled with a new environment, unfamiliar peers and teachers, and expectations for academic and social behaviors, can be overwhelming (Odom et al., 2004). Educators need to foster a sense of belonging for the children through helping them build caring relationships with the other children and adults in the classroom (Cross, Traub, Hutter-Pishgahi, & Shelton, 2004). Academic experiences also need to be designed so that the children can be successful through appropriate support, including adaptations, modifications, and other resources (Schwartz et al., 2002). A sense of belonging, caring relationships, and academic success increases the children’s confidence so that they can flourish and grow throughout their school experience (Warren, Martinez, & Sortino, 2016).

Increasing Parents’ Confidence

Viewing parents as an essential component in the school community means meeting their needs so they can better support their children. Many parents of preschoolers with disabilities are unsure of their role in the school and in their child’s life which can affect their sense of efficacy and confidence to be a partner in the preschool program (Gershwin Mueller et al., 2009). Parenting self-efficacy, belief about competency in performing the role as a parent, has been acknowledged in the United States as a strong predictor of particular parenting practices. It is also considered a mediator for specific parent (e.g., maternal depression) and child outcomes (e.g., child temperament) (Coleman & Karraker, 1998). Parents with high sense of self-efficacy exhibit less stress, have more knowledge about the child development process, and better understand their role as parents. This can lead to more resilience when faced with the challenges of raising a preschooler with disabilities (Suzuki et al., 2009).
Educators can foster self-efficacy in parents by providing them with clear information about their child and the school program as well as resources to increase their understanding of their role and ability to perform in it (Hess, Teti, & Hussey-Gardner, 2004). Being included in their child’s educational experience as partners also increases parents’ confidence and feelings of worth. Inclusive preschool environments where parents are genuine partners foster self-efficacy and confidence for all (Warren et al., 2016).

Step-Up Full-Inclusion Preschool Parents

Parent participants in the Step-up Program identify gaining confidence as being a salient part of the full-inclusion experience that brings success to their family. This includes both increases in the children’s confidence and increases in the parents’ confidence. For many of the children, this is their first time to be fully engaged with others socially. As the children grow in their knowledge and skills, so does their confidence. Learning to communicate with others gives them the ability to fully participate in their worlds at school and home. Parents’ level of confidence has also increased as a result of being involved in the full-inclusion preschool program. Some of the parents have hope for the first time and a sense that their child can and will be successful in the future. These parents feel that they too are included in the school and benefit along with their children.

Increases in the Children’s Confidence

The Step-up parents discuss how, due to the nurturing environment and growing skills, their children’s confidence has soared. Most of the children’s speech/language was delayed with some not speaking at all before preschool. All children were speaking by the end of their first year in the program, many in just a few weeks as a result of the emphasis on language development in the classrooms and support from the speech/language specialist. One child’s services for speech/language were discontinued at the end of preschool due to increased abilities.

Our child didn’t speak before coming to the program. He is now a very sociable, loving, energetic, capable, and confident communicator — asking many questions. I thought the process would be much slower but in the span of less than two years he reached great milestones. (parent)
Increases in the Parents’ Confidence

The Step-up parents report their own confidence has also increased. At enrollment, many were confused and unsure of the process or what was happening to their child. They were afraid and worried about their child’s future. Some believed there was no hope, at first, that their child could be successful in school or life. Others express they did not know how to support their child at home or how to work with the school. Their doubts have disappeared as a result of being included in Step-up with opportunities for their own growth such as trainings on Conscious Discipline and other aspects of the program and parenting. Observing their child’s academic and social growth, parents gain confidence in their own abilities to be parents and confidence that the school will support their child’s achievement. School staff, including the specialists, work side-by-side with parents on ways they can enrich the learning in the home to better support their children.

SUPPORTING PARENTS AND THEIR CHILDREN WITH DISABILITIES

Maria

I can recall the first IEP meeting to discuss a possible preschool placement with support services for my now 11-year-old, middle son. I felt like I was in a panel interview. I was nervous and anxious to learn what they had found after all the tests. There I sat, the school district staff on one side of the very long table and me on the opposite side alone, not knowing what to expect. I remember the speech therapist saying, “Daniel has some problems with speech, mostly with pragmatics.” Then the behavioral therapist chimed in adding that she had noted some behavioral issues. I was sad but honestly happy to hear this because it meant he would get help in preschool and go into kinder one step ahead! I silently cheered -Yay! and then came the BUT. “But he needs to have three deficiencies in order to qualify for our preschool program.” I wanted to cry. I wanted to scream. I wanted to tell them how he would not make it in a regular preschool setting without special services. I remember saying a couple of things but I can’t recall what they were — just that they made no difference. I walked out feeling defeated, let down, and more alone than ever. All I wanted was a place for my son to learn and to
Daniel did not succeed in the city preschool where there were no accommodations or teachers that understood his disabilities. He also “failed” kinder, not academically but in a way that is most important at that age: he made no friends, had very little social interaction, and HATED school. He still hates school.

Unfortunately, most of us, as first time parents, walk away because we are fighting alone and without direction. We may have just found out that our perfect child is not perfect, or we may suspect that something is not right. We have internal conflicts as to what to do and we are exhausted by the extra dedication a child with special needs requires. So we walk. We walk away defeated and without knowing that our child has the right to FAPE [Free Appropriate Public Education] and the school has the obligation to provide it.

According to Soukakou (2012), high quality inclusion is more than simply enrolling children in a classroom. It involves the quality of the supports and practices, classrooms that are “individually and dynamically goal oriented” (p. 480), and ongoing “specialized instructional strategies and interventions” (p. 480). High-quality inclusive classrooms provide opportunities for all children to successfully engage in the curriculum with appropriate adaptations, modifications, and other means to support the students with disabilities (Odom et al., 2002; Schwartz et al., 2002).

Support in an inclusive environment extends beyond the child at school to their families. Research on psychological adjustment of parents of children with disabilities reveals they experience a wider array of challenges than parents of children without disabilities (Achilles, McLaughlin, & Croninger, 2007; Brown & Pacini, 1989). This is intensified when the child has two or more diagnostic conditions (Janssen, Schuengel, & Stolk, 2002). Excessive time demands, extensive care, and worry about the child’s future can lead to parental stress affecting their well-being and role as caregivers (Benn, 2012; Soodak & Erwin, 2000). These parents also often experience self-blame or guilt and report insufficient supports, feelings of helplessness, and even depression (Broomhead, 2013; Francis, 2012; Moses, 2010). A study of 148 Latina mothers of children with intellectual disabilities found that 50% experienced depression (Blacher, Shapiro, Lopez, & Diaz, 1998). These symptoms can result in long-term health declines for parents and affect their ability to fulfill goals they have for their children (Smith & Grzywacz, 2014).

Providing resources to the families of children with disabilities is identified as an effective element in the research on promoting parent-school
partnerships (Cohen, 2013; Turnbull et al., 2006). This can include connecting parents to other parents who have had similar experiences (Gershwin Mueller et al., 2009) or to community agencies that can provide access to critical information regarding parental rights and services for their children, support for their children functioning at home, and opportunities to communicate with various professionals related to their children’s disability (Aceves, 2014). Increasing parents’ knowledge and support can lead to higher levels of efficacy and their ability to advocate for their children’s disability (Olmsted et al., 2010).

**Step-Up Full-Inclusion Preschool Parents**

“The staff genuinely all have a smile on their faces daily. They love what they do and support all of the children and their families” (parent).

Parents in Step-up identify the support provided in the inclusion program as one of its greatest strengths. This support is seen at various levels and through a variety of means. Support in the classrooms includes: a small educator to student ratio (1:5), specialists, teachers with special education credentials and experience in general and special education, instructional aides who love what they do, individualized attention with adaptations and modifications, and a warm and caring environment. Teachers, instructional aides, and specialists all work together to support the children in the classroom through individualized learning experiences and engaging activities with peers.

Parents too feel supported through trainings, resources, and personal outreach by staff and administrators, often far beyond the traditional role of educators. Surveys and personal contacts with parents provide data on topics for family workshops. The trainings are provided at various times of the day to allow more parents to participate such as immediately after a.m. or p.m. drop-off at school, an hour before pick-up, or in the evenings. Extended family members or others close to the family are also encouraged to participate in the workshops and be a part of the program widening the sphere of support to parents as well as the children. The workshops often include information about the curriculum in the Step-up program, effective strategies parents can use at home with their children, and connections to resources in the community.

Support at Step-up is often seen by the parents as being provided on an individual and as needed basis. One parent’s story includes how she became overwhelmed and then depressed about her son’s condition. She admits
drinking excessively and soon her family and marriage were suffering. The staff supported her and her son throughout rehabilitation. This included visiting her at the rehabilitation facility, coming to the family home, and spending additional time outside of school with her son. This mother attributes their success to the staff who all “not only believe in children but all people” (parent comment).

CONCLUSION

Research suggests inclusive educational programs at the preschool level can significantly benefit children and their families (Odom et al., 2002). However, fewer than a third of preschool children with disabilities have the opportunity to participate in them and these inclusion programs vary greatly in quality and structure (Odom et al., 2004, 2011; OSERS, 2015). Furthermore, numerous barriers prevent parents from being included in their children’s preschool education, lessening the chances of success for the children even more (Aceves, 2014; Gershwin Mueller et al., 2009; Lian & Fontanez-Phelan, 2001).

Listening to the voices of parents about their children’s experiences in inclusive preschool programs highlights the importance of a school culture that: values people and inclusion, involves families in all aspects of the program, shares parents’ high expectations for students’ academic and social growth, establishes communication and means for collaborating among the staff and with families, builds confidence in children and parents, and provides many resources to support the children and parents in the educational journey. Educators must establish relationships with families and embrace them as genuine partners in their children’s preschool experience.

The reciprocal relationships that exist between child, family, school and indeed community are far reaching. To talk of a “link” between the school and home is to undervalue what actually takes place…In reality it is not so much that families take part in the life of the school but rather that, together with the children and the teachers, they are the school. (Learning and Teaching Scotland, 2006, p. 17)

Successful outcomes for preschool children with disabilities and their families can result when they are involved and participate in meaningful ways — when they are valued and included in schools that belong to all.
REFERENCES


APPENDIX

THE STEP-UP FULL-INCLUSION PRESCHOOL PROGRAM

Upland Unified School District, Upland, California

The Step-up Full-Inclusion Preschool Program opened in September 2007 with two classes and, due to word spreading about the high levels of success it brings to all students, the 14th classroom opened in 2015. Instead of busing preschool students with disabilities out to county-run schools, these tots in this Southern California public school district attend the full-inclusion program that is located in two of the district’s low-enrollment elementary schools. The children are now able to stay in their own community and learn alongside of their neighborhood peers. Best of all, after experiencing this program, approximately 90% of the students with disabilities are able to transition into a general education kindergarten class with minimal support (Warren et al., 2016).

A major component of the Step-up curriculum is that it is infused with language, play, and music. Students attend a three-hour session Monday through Thursday which is taught by teachers who are experienced and fully credentialed in early education and special education. Highly trained instructional aides provide additional support in the classroom allowing a 1:5 instructor to student ratio. A speech and language pathologist and occupational therapist also work with all students once a week. These support specialists along with a school psychologist and nurse regularly collaborate with teachers and parents in developing behavioral intervention plans and supports to meet the unique needs of all of the learners.

The leadership team of this innovative program has dedicated two hours every Friday for teachers, aides, and support staff to plan, communicate, and collaborate. The district administrators have been responsive by providing necessary resources and supporting the growth of the program. Most of all, through caring this school district has nurtured and integrated students with disabilities and their families back into the neighborhood schools.

Stepping up with HEART ♥: Program Mission

The Step-up Preschool program mission seeks to “provide excellence in education by celebrating the unique worth of each member” in the school
community. This includes parents and staff as well as students so that all benefit from the program. The program seeks to fulfill this mission by “treating all individuals with compassion, integrity, and acceptance while promoting a commitment to lifelong learning.” The acronym HEART defines the program:

- **H** = Heart for the unique needs of all learners
- **E** = Environment is nurturing
- **A** = Developmentally appropriate approach
- **R** = Language-rich curriculum
- **T** = Team of credentialed teachers, specialized staff, and families (Warren et al., 2012).