

# People & Families

NEW JERSEY COUNCIL ON P...

WINTER 2015

**Professionals Guiding Families  
Through the Transition to Preschool**

**GIVING THEM  
THE SUPPORT  
THEY NEED**

Anna and  
Fabian Santos

# C O N T E N T S

## **6 FROM THE EXECUTIVE DIRECTOR, DR. ALISON LOZANO**

### **A Final Note and Then on To Albania**

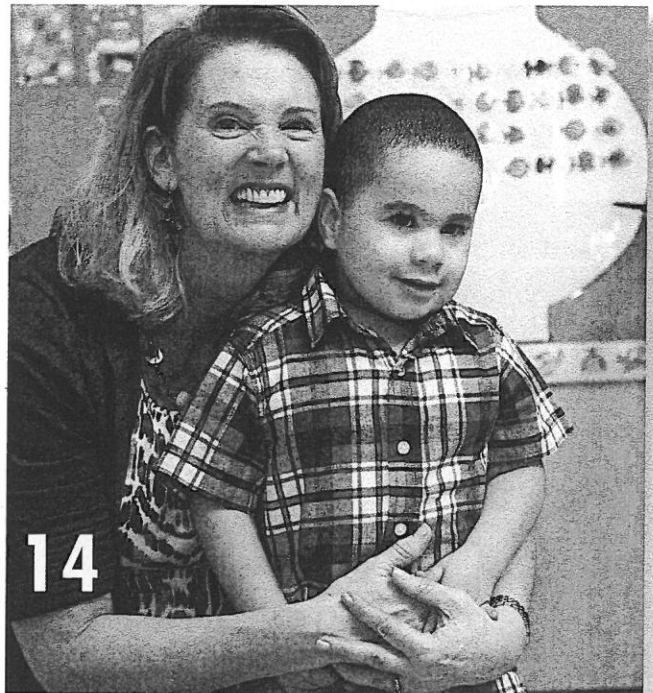
So, as I end this most rewarding position as the Executive Director of the NJDD Council, I wish the Council membership, Council staff and magazine readers well. I am sure the person who is hired as the new Executive Director will find this position equally personally fulfilling as I have for this past almost nine years.

## **7 NEWS & NOTES**

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## COVER STORY



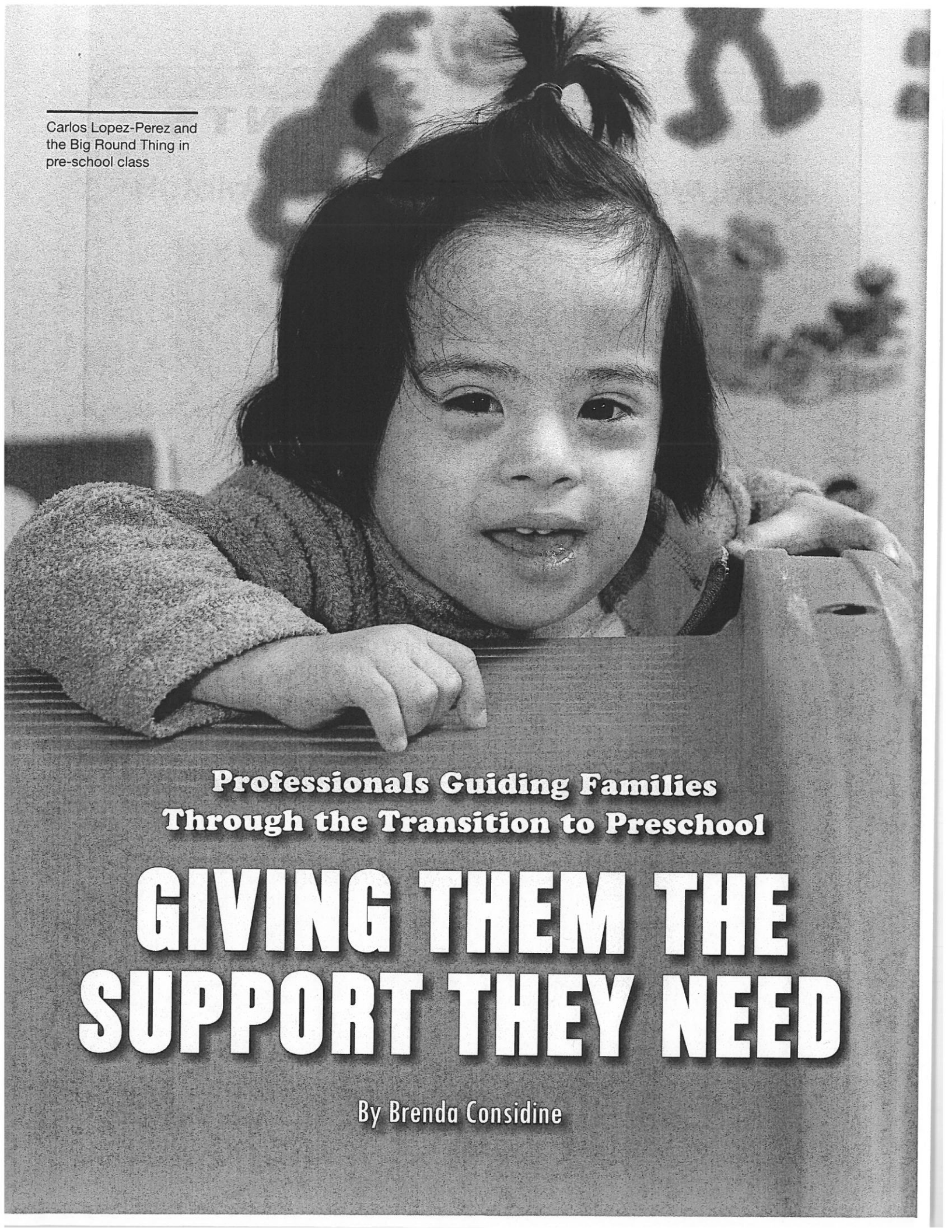
## **14 GIVING THEM THE SUPPORT THEY NEED**

### **Professionals Guiding Families Through the Transition to Preschool**

The two systems, Early Intervention and the schools, need to work more closely together to make it smoother and more connected for students and parents

Front Cover: Anna and Fabian Santos  
*Photo by Rebecca Shavulsky*





Carlos Lopez-Perez and  
the Big Round Thing in  
pre-school class

**Professionals Guiding Families  
Through the Transition to Preschool**

# **GIVING THEM THE SUPPORT THEY NEED**

By Brenda Considine



Parents chat and laugh as they make their way down a hallway framed with metal braces, walkers, special strollers, and other adaptive equipment at North Jersey Elks Developmental Disabilities Agency (NJEDDA). With a toddler by the hand or a baby perched on a hip, mothers pour into a sunlit room and take a seat on the carpeted floor among brightly colored mats, balls, and toys.

They have arrived for the Special Toddler Playgroup, a program launched two years ago to provide support services for children ages one through three, who have physical and developmental delays. They take part in activities such as language stimulation, socialization, educational games, and therapeutic movement, while moms share smiles, tears, and tips with each other.

"The playgroup is a return to our roots, when families brought their children in for groups, and early intervention services were offered in our agency," says Dr. William Weiss, executive director of the Clifton-based NJEDDA. The agency offers the group twice a week at no charge to families. "Our goals are to help these children reach their maximum potential, and to offer support for their parents," adds Weiss.

For more than 10,000 infants and toddlers with developmental delays, New Jersey's Early Intervention System (NJEIS) can be a lifeline of hope. The system, funded through Part C of the Individuals with Disabilities Education Act (IDEA), offers free evaluation for children birth through age three. If determined eligible for Early Intervention Services, the family receives an Individualized Family Service Plan (IFSP) mapping out needed services, such as speech therapy, physical therapy, occupational therapy and developmental therapy. The evaluation and IFSP are free, but the services and therapies themselves are provided on a sliding-fee basis. In some cases, private insurance is used.

While NJEDDA no longer provides services as part of the Early Intervention System, they

offer the toddler group because the agency is committed to providing outreach and support to underserved families, particularly as they transition from the early intervention system to the special education system.

## **Transition to Preschool**

All toddlers who receive early intervention services are considered "potentially eligible" for special education, but not all will receive special education when they leave the NJEIS at the age of three. Some children are found eligible for special education preschool services by the local school district, but others are not. Some families simply 'opt out' of the system.

The transition process, managed by regional service coordinators, is designed to put families in the 'driver's seat,' empowering them to make decisions. But according to many of the professionals who provide direct services and therapies day-in-and-day out to children and their families, not enough is being done to ensure that parents are ready for this role.

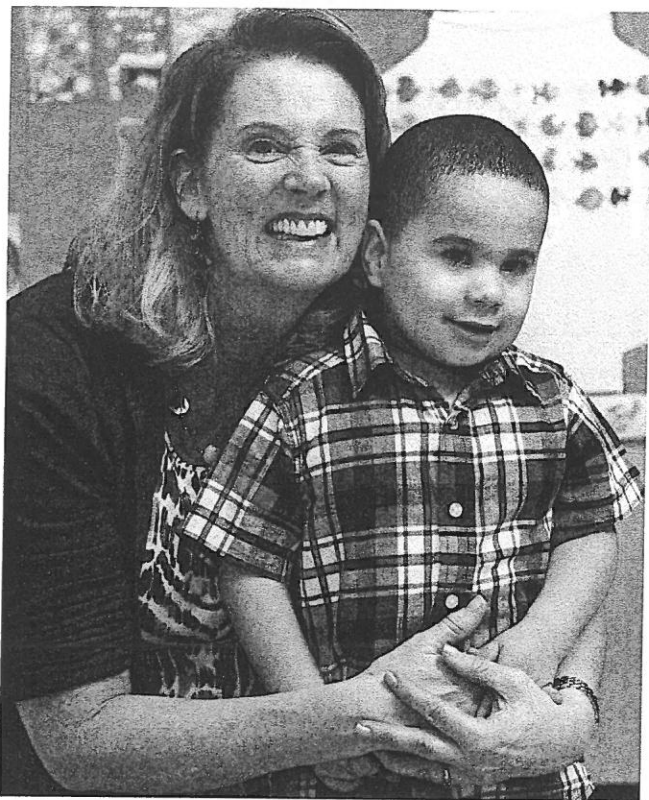
"Most families need a lot more hand holding in order to get through the transition process," says Joyce Salzburg, a licensed clinical social worker who has been in the field of Early Intervention for more than 25 years. Salzburg, co-founder and CEO of Sunny Days Early Childhood Developmental Services, which serves more than 1,700 New Jersey families each week, sees many parents of toddlers who lack the information and skills they need to make informed decisions.

"It is like giving a four-year-old the keys to the car and telling them to drive. These parents are told they are in a role of decision-maker, but they do not know the rules of the road. We just do not offer enough direct support and training for families," she concludes.

## **The Role of Therapists and Providers**

One of the difficulties is the lack of a formal, ongoing role for the therapists and providers in the transition process.





Fabian Santos with Anne Foster

According to Patti Carlesimo, chair of the board of trustees for the Alliance for the Betterment of Citizens with Disabilities (ABCD) and chair of ABCD's Early Intervention Providers Association, the mandatory 'transition planning meeting' that occurs when a child is two years old is the only formal opportunity for service providers to support the child's transition. Transition support is provided through a regional service coordinator who may not know the child, the local community or the therapists who provide direct services.

Anne Foster, a physical therapist who consults with parents in NJEDDA's Special Toddler Playgroup, sees a need for better parent support, and a more direct connection between early intervention service providers and the local school district.

"I have been providing in-home early intervention services for 15 years and have never been asked by a Child Study Team (CST) member for information about a child, or for recommendations about what a child needs," Foster says.

"The professionals who work directly with these children have a lot of information and

insight, but it gets lost. After the initial transition meeting, children are evaluated by the district therapists. There is no venue for the EI therapists and the district therapists to collaborate about recommendations or placement for a child," she adds.

## Advocacy and Support

Early intervention providers claim that many families want the therapists to stay involved and come to meetings with the school district, but that is not allowed—at least not in an official capacity. Providers believe that their absence at the table is a problem for families of young children, especially when local school districts deny eligibility for special education, limit service options, or, in some cases, fail to follow the law.

Foster shares the story of one Essex county family who was told by the Child Study Team at the first individual planning meeting that it is the district's policy not to send children out-of-district under any circumstance. After trying the in-district program for several months, the family felt their child's needs were not being met, so they moved to a different district, which placed the child in an out-of-district, specialized program.

Early intervention providers stressed that while families have the right to appeal, those who do not speak English or know their rights may simply give up.

That was not the case for Ana Pérez. Her 4-year-old son, Fabian Santos now attends a specialized preschool program at NJEDDA. Through an interpreter, Pérez described her dreams for Fabian, and her tireless work advocating for him as he moved through the early intervention system to preschool.

"I feel like I have been blessed by God that Fabian got the help he needed and he got into this preschool," says Pérez. "I hear horror stories from other parents. They face obstacle after obstacle and in the end, the district just tells them 'no, your child cannot have these services and will be going to the local program.' Other parents ask me how I did it. They want me to help them."

Pérez adds that while her study team did suggest in-district options, ultimately, they agreed

that the private program she found for Fabian represented the most appropriate placement for preschool.

Pérez had done all of her homework. She had video of Fabian, tracking the progress he made at the toddler playgroup where he learned to talk, walk and run. She also had medical reports, evaluations, and documentation showing that her son needed intensive therapies, adaptive equipment and other specialized supports, in order to benefit from special education.

“If Fabian’s mom was not such a good advocate, I am pretty sure he would have been placed in a less intensive program,” says Foster.

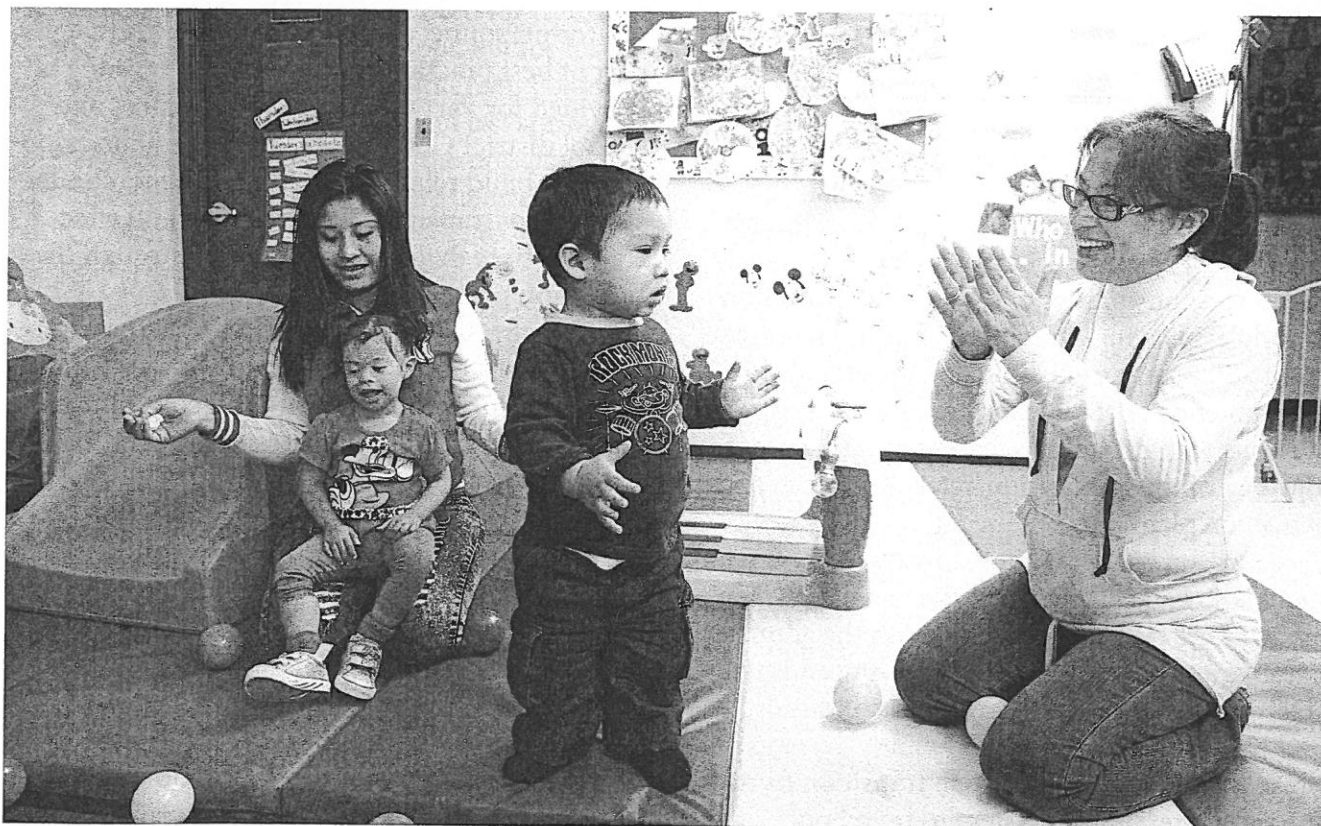
## The Intersection of Two Complex Systems

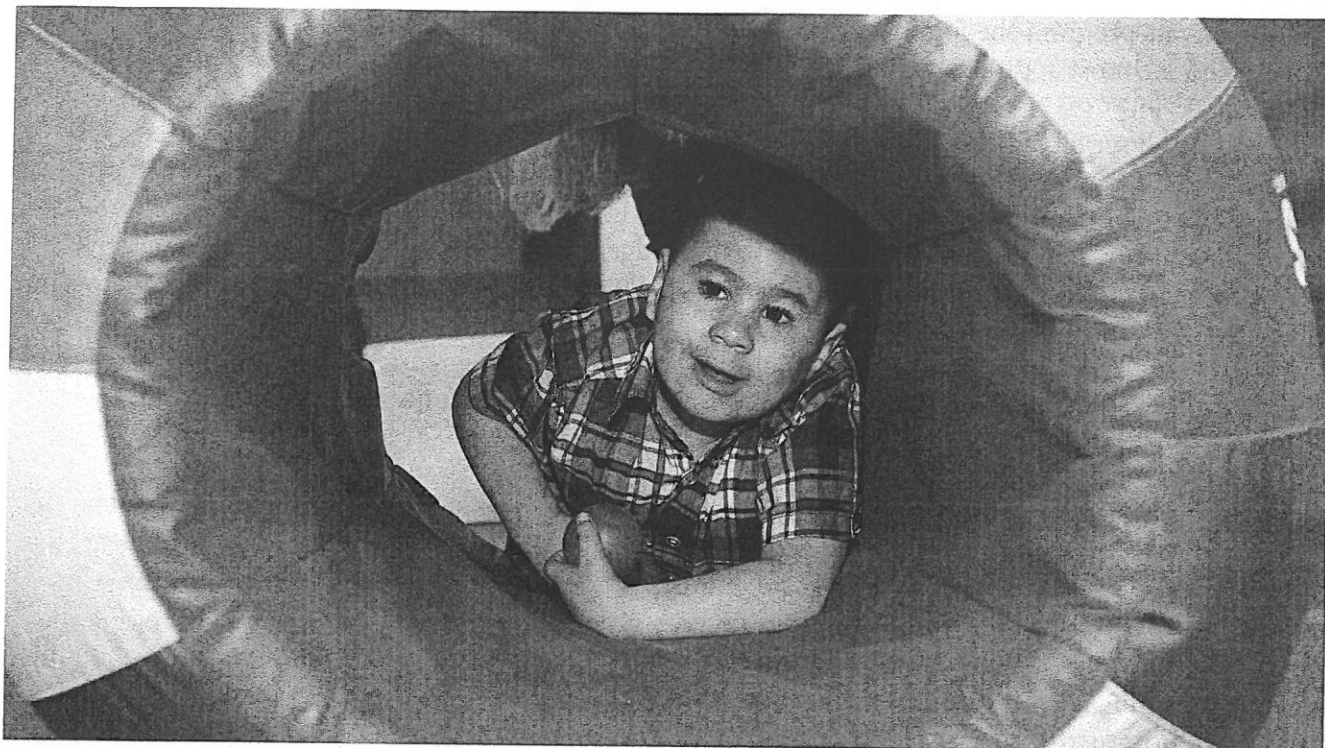
One of the biggest challenges families face as they transition from Early Intervention to preschool services is the structure of the system itself. Early Intervention (Part C of IDEA) is housed in the New Jersey Department of Health. It is a multi-

tiered system that includes four Regional Early Intervention Collaboratives (REIC) that plan and coordinate services, and provide a point of entry into the system. Direct services and therapies to children and families are not provided by the REIC, rather, they are delivered by local provider agencies. Special education services (Part B of IDEA) are housed in the New Jersey Department of Education (NJDOE). It uses a highly local system, in which direct special education services are planned, administered, and delivered by one of New Jersey’s 611 local school districts.

Terry Harrison, Part C Coordinator for the Early Intervention System in the NJDOH acknowledges that there are some “expected challenges” during the transition from early intervention to preschool, especially considering the number of school districts in New Jersey, and the shift from Early Intervention’s focus on “developmental services,” to special education’s focus on “free and appropriate” public education. She adds that late referrals to the early intervention system,

Mateo Ruiz intent on the hands and Jenneve Inocenrio on the many colored balls around the classroom, with staff members at an Elk’s pre-school session.





Fabian Santos coming out at the Elks DD agency's pre-school in Clifton

as well as complex, and irregular residency and registration requirements that vary from school district to school district can delay the eligibility determination for preschool services and hinder smooth transition.

### **Bringing All The Players Together**

In 2012, the Health and Education departments signed a 5-page interagency agreement delineating the responsibilities of each for the transition of toddlers leaving early intervention. The agreement addresses notification and referral of children potentially eligible for preschool services for students with disabilities, parent opportunity to 'opt-out' of the notification/referral process, and transition planning.

Harrison believes that the interagency agreement is strong evidence that the two departments are working closely together at both the administrative and service delivery level. She adds that interdepartmental staff meet at least monthly, and that leaders in the system jointly develop and present regional workshops on transition from the early intervention system to preschool.

According to Harrison, the challenges around transition are being addressed through joint training and local networking opportunities for personnel and families. She adds that, as part of best practice, joint transition training is provided for Part C Service Coordinators and school district Child Study Team members in order to build relationships and common understanding of transition requirements and effective practices that support families through the transition process.

Salzburg and other providers agree that these steps are part of the solution, but she sees a much larger role for those who work directly with children and families. She believes that greater collaboration between local early intervention providers and local school districts is critical.

"CST members need more training about early intervention," Salzburg explains. "Effective transition to preschool is an entitlement, and we have to take that more seriously. If all the players in the two systems worked together more, and supported families throughout the process, I think we would do a better job here in New Jersey."