



# the Link



healthy families  
new york

the children of today are tomorrow's parents @ los niños del presente son los padres del futuro @ les enfants d'aujourd'hui seront les parents de demain

## The Story of Yubelkys, Bienvenido and Little Kelvin, or, How One FSW Made a Huge Difference in the Life of One Family

**Pam Balmer**  
**Prevent Child Abuse New York**

Lucy Soriano, FSW at Best Beginnings in Manhattan, began working with a mom, Yubelkys Ventura, and a dad, Bienvenido Abinader, when their baby Kelvin Abinader was almost one week old. Lucy's warmth and enthusiasm worked their magic, and the family was engaged in the program right from the start, enjoying weekly home visits that always included Bienvenido and Kelvin and often Yubelkys and her older son and daughter, Jose and Brenda. And so it continued for the next eleven months—visits that always had parent-child interaction and child development as their central theme. With handouts, information and activities Lucy joined the family in marveling as Kelvin grew and developed along a smooth trajectory that showed up in excellent scores across all domains on the four-month and six-month ASQs. The eight-month ASQ was not quite as stellar as the first two, but it was fine, especially when Lucy considered what she knew to be true of child development: every child proceeds at his own unique pace. Kelvin was pointing at things, enjoying his image in the mirror, and beginning to use words like "one", "Mama" and "Papa."



Lucy Soriano, FSW; Yubelkys Ventura, Kelvin Abinader, Bienvenido Abinader

## Children with Special Needs

At about eleven months Lucy began to notice a change, and the twelve-month ASQ confirmed that Kelvin's development had slowed and actually started to go backwards; he wasn't retaining skills he'd begun to develop earlier. Lucy shared the under cut-off scores with the parents and together they planned for Zenobia Saunderson, the Child Development Specialist at Best Beginnings, to come out and do a screen using another tool, the Bayley. That screen confirmed the concerns raised by the ASQ and Lucy encouraged the family to have the Early Intervention Program (EIP) do a thorough evaluation. Neither parent agreed at first. Mom said that it was typical for children in her family to be late walkers and talkers; both parents wanted to give Kelvin more time. Lucy did what is one of a concerned FSW's most challenging jobs: with the help of her supervisor at the time, Onelfa Guillen, she saw that she needed to slow down, listen, and be patient. Over the next couple of months, using curriculum, information, and activities, she helped the parents observe for themselves that Kelvin's development was outside the range of typical child development. And Lucy consistently reinforced that the objective wasn't to label Kelvin but to get him services that could be helpful. Finally at around 14 months the family agreed to an evaluation with EIP. Lucy attended the evaluation too. It confirmed delays and qualified Kelvin to receive therapy through EIP. Yubelkys wasn't as ready as Bienvenido, who as a stay-at-home father had developed a very close bond with the baby. He agreed to and welcomed EIP services.

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## Spring 2007

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## HFNY Goals

- To systematically identify overburdened families in need of support
- To promote positive parent-child interaction
- To ensure optimal prenatal care and promote healthy childhood growth and development
- To enhance family functioning by building trusting relationships, problem-solving skills and support systems

## theLink

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The LINK is published three times yearly as a joint venture of Prevent Child Abuse NY and the New York State Office of Children & Family Services

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# Healthy Families New York Updates from OCFS

**Joy Griffith**  
**Program Contract Manager**  
**NYS Office of Children & Family Services**  
**(OCFS)**

Hi Everyone!

I am sad to announce that Rona White-Allen will be retiring at the end of May. Rona is the Program Contract Manager for many of the programs in New York City and Westchester. Rona took a lead role in organizing the first all-staff Training Institute in Saratoga in 2002. It was so successful we had another one in 2005, and we are beginning to plan one for 2008. Since Rona came to HFNY, we have grown from 12 programs to 29. Rona is a true believer in HFNY and the benefits it has for all of our participants. She has been a dedicated member of the HFNY team. We have all really enjoyed and appreciated the opportunity to work with Rona and wish her the best in her retirement.

On a brighter note, we are happy to welcome Myrna Bridges to our HFNY Team as a Program Contract Manager. Myrna comes with much expertise in serving families in need and we are excited to have her with us.

### Leadership Team Meeting

A State-wide leadership team meeting took place in Saratoga, NY in March. The event involved programs sharing resources, introduction of the updated policy manual, and discussions about other policies related to the HFNY program. A good deal of progress was made, and the Program Policy Manual should be completed by the summer of 2007. Also, John Heck (SUNY) revealed the HFNY website! Check it out at [healthyfamiliesnewyork.org](http://healthyfamiliesnewyork.org).

Everyone was impressed and enthusiastically thanked John for his hard work.

### HFNY Home Visiting Council Meeting

The HV Council met in Albany in March to continue work on a new strategic plan. John Heck (SUNY) provided a preview of the HFNY website. All present believed the new site would be a great tool to get the word out about HFNY. In addition, HFNY would like to thank members of the Trust Fund Advisory Board who joined us for lunch, as they provided information about their strategic planning process. It was great to hear that their hard work paid off, and it gave the council inspiration to continue.

### New York Loves Safe Babies Calendar

The OCFS Family Trust Fund, in collaboration with the NYS Department of Health, published an 18-month calendar, with artwork from children in kindergarten through 12th grade from various schools and placement centers throughout New York. Each piece of art is a reflection of safety concerns that children face, and every month includes a safety tip and fun fact. This is a valuable resource for staff and the families they serve. Programs that have placed orders for these calendars should receive them by the end of April.

### HFNY Request for Proposals

HFNY is expanding! In all, 55 proposals were received for the HFNY request for proposals, which totaled roughly \$28 million. Many of the proposals were outstanding and included areas in high need. OCFS expects to fund 6-10 of the proposals. It was great to see so many agencies who believe in the HFNY model and the benefits of home visiting. This growth is an exciting venture for all.

## Hello HFNY!

My name is Myrna Bridges and I am the new Program Contract Manager. I look forward to working alongside Tina, Bernadette, Rona, Maria and Joy.

What do I bring to HFNY? Prior to this position, I have worked with populations that include developmentally disabled adults and children, adjudicated adolescents, adolescents diagnosed with mental health and/or behavioral disorders, adults with dual diagnoses (such as Mentally Ill and Chemically Addicted, and Mentally Ill and Developmentally Disabled), survivors and families of domestic violence, individuals in the criminal justice system, and pregnant and parenting teens. In addition, I provide trainings in harm reduction and motivational interviewing, effective listening and communication skills, ethics and boundaries, and substance abuse and co-occurring disorders. I am also an adjunct instructor at Hudson Valley Community College and Bryant and Stratton College where I teach classes in criminal justice, chemical dependency, and human services. I am completing my PhD in human services with a specialization in criminal justice. In my spare time I coach 2nd and 3rd graders in basketball, and enjoy spending time with my 8 year-old twins and 14 year old daughter.

I look forward to meeting everyone involved with the HFNY program. As a new member of the growing team, I look forward to learning and growing with Healthy Families!

## ***Yubelkys, Bienvenido and Little Kelvin, continued from page 1***

After many months of therapy nothing seemed to be changing. Lucy got curious and, with the family's permission, scheduled some home visits for therapy time. She noticed right away that the therapist and the parents seemed to enjoy each other's company, but the therapist and Kelvin weren't connecting. After Lucy pointed this out to the therapist and the parents, Bienvenido decided it was time to arrange for a different therapist. Though he wasn't ready to accept the diagnosis of autism that came after a number of additional evaluations, Bienvenido knew that he wanted the best for his baby, and once the new therapist came into the picture things began to click and Kelvin made progress. Lucy observed that Bienvenido enthusiastically became the primary therapist, continuing the EIP therapist's activities daily and teaching them to the rest of the family, who also got actively involved. Lucy scheduled occasional visits when the therapist was in the home. She says, "I learned so much from being there!"

Now at age four Kelvin has transitioned from EIP, which serves children up to age three, to services provided through the school district. Recently Bienvenido, with Lucy's encouragement, went to bat for Kelvin and advocated for him to continue receiving the Applied Behavioral Analysis (ABA), he'd received through EIP, even though the school district said he didn't need it. ABA is a specialized therapy for individuals with autism that breaks behaviors down into their smallest components and then teaches and reinforces each component. The goal is to string the mastered components together to build new behaviors into the person's repertoire. All along Lucy had been paying attention and doing important networking during trainings she'd attended for her job, and she kept offering resources, contacts and phone numbers to Bienvenido. He used the information, and after many phone calls, faxes and brave persistence, Bienvenido scheduled a meeting with the "big wigs," and, accompanied by his wife, advocated for and won ABA for his son. Lucy recalls, "After the meeting he called. 'Lucy, I won!' He showed me the papers and Kelvin will get ABA at school and extra services at home." The whole Best Beginnings staff cheered when they got the news, having become very familiar with Bienvenido when he came into the office to send his faxes or gather information and resources.

It has been a tough road for the family and for Lucy. While the parents struggled to come to grips with their child's diagnosis of autism, often blaming themselves and each other, and finally reaching a level of acceptance when Kelvin was three, Lucy struggled with her own feelings. She knew she was doing her work and bringing out information and working with the parents and the child, but she wondered if her supervisor thought she was doing her job. "I felt like a failure; like I must have missed something. I wondered how it would feel to be the parents. Their IFSP goal was for him to walk by 12 months. At 15 months he still wasn't walking." Her supervisor helped her through this tough period by assuring her that she was doing a good job and by sharing information about autism. Lucy's co-workers listened and supported her too. Lucy says, "It's been nice, and happy, and sad. Bienvenido doesn't give up; Mom too. I'm so proud of them; they never stopped once!" Acceptance is a continuing process. Even now Kelvin's parents' dreams for him are still the same dreams every parent has, according to Lucy. "They want a perfect child. Daddy fought for ABA so that Kelvin could be like every other child, but he won't be. When I talk to him about it Bienvenido says, 'One day I'm not going to be here and I want for him to be able to do for himself.'"

# Conversation with an Early Intervention Official

**Pam Balmer, Prevent Child Abuse New York, interviews Anne Jernigan, an experienced Early Intervention Official (EIO) from Chemung County.**

## **You are an EIO, that's Early Intervention Official. What is your role?**

I'm responsible for making sure we are following the state regulations for the Early Intervention Program (EIP), and I'm responsible for making sure parents' concerns are heard and addressed. I maintain relationships with service providers, and I'm also involved with the transition of little ones from EIP to CPSE (Committee for Pre-school Special Education), which is the next step for little ones who still need services after they turn three.

## **What drew you to this work?**

I was a Speech Pathologist for 15 years and I saw things I thought could be done better. Little ones don't just need services, they need quality services. Quality counts!

## **Can you give a brief definition and description of Early Intervention?**

We are part of Child Find (part of the Individuals with Disabilities Education Act) so we are the single point of entry for families. Our goals are to make sure all children have insurance and a medical home and to identify and address developmental disabilities. EIP Service Coordinators (SC) facilitate Medicaid enrollment and/or assist in getting children connected with a medical home. Physicians are responsible for keeping track if they haven't seen a child for regular well-baby visits or they've lost touch with the family, then as part of Child Find our SC's go out to see if they can get the family and the physician re-connected. For our EIP responsibilities, we take referrals from any parent, home visitor, babysitter, physician, clinic—anybody who is concerned that a child might have a delay. We now do very few developmental screens, since physicians have become responsible for them.

*continued on page 4*

## **Early Intervention Services**

The Early Intervention Program offers a variety of therapeutic and support services to eligible infants and toddlers with disabilities and their families, including:

- Family education and counseling, home visits, and parent support groups
- Special instruction
- Speech pathology and audiology
- Occupational therapy
- Physical therapy
- Psychological services
- Service coordination
- Nursing services
- Nutrition services
- Social work services
- Vision services
- Assistive technology devices and services

The program serves children from birth up to age 3.

## Conversation with an EI Official, continued from page 3

We take a referral, and an SC begins the intake process that includes gathering information about the child, making sure the family understands the EI Parent Guidebook and what their rights are, and we emphasize that all of the services we provide or arrange are voluntary and completely free of charge. The family has the freedom to choose the evaluator for their child and we explain their options for choosing their Ongoing Service Coordinator.

The developmental evaluation is completed by licensed therapists. In order for a child to qualify for EIP services, the evaluation must show a 33% delay in at least one developmental domain, or a 25% delay in two or more areas. If neither of these criteria is met and the parents feel strongly that their child needs services they are welcome to discuss the evaluation with the EIO. Guidelines for doing this are included in the Parent's Guide.

### What have you found parents appreciate the most about EI?

We do family surveys twice a year and what

they tell us is that the families really appreciate the Service Coordinator's involvement. This is a complex process and it can be pretty daunting—especially for families that struggle with even the simplest things. Knowing that they have an SC who hears them and advocates for them throughout their time in the program is very powerful. Knowing a broad range of resources in the community and advocating for the families is a big part of the SC's job. I can't recall the last time we got a complaint.

### Are there common things families struggle with?

It really is individual, but scheduling is always an issue; therapists are at such a premium. When you receive services you are opening up your home to a stranger, but we find that once a relationship gets established, families become very comfortable. With higher-needs kids, acceptance can be difficult. We get these kids early, so we are there as families are coming to terms with the idea that their child has a delay. We're often the first ones on the scene.

### What about language barriers, what happens then?

The regulations are clear—you have to provide an interpreter so that services can be provided in the language spoken in the home. In our area we most frequently need Mandarin Chinese interpreters.

### In our HFNY programs we do regular periodic ASQs starting at four months. Are there other ways home visitors can help parents keep tabs on their baby's development?

Developmental milestones or developmental checklists are great. And it's important to keep kids connected with their physicians.

### How can HFNY, EI and the medical and therapeutic community best collaborate to support families?

Bottom line is communication. We're starting to see more and more referrals from physicians. There has been a real culture change in the medical community over the last few years. An investment from EI and programs like HFNY has helped to make that happen. And don't forget, a parent can request an EI evaluation even if we don't suspect a problem. Part of the EI enrollment process is that every child has to have a physical as part of the evaluation and before a prescription can be written for services. If a child doesn't have a doctor, EI has to make arrangements for that.

### Any breakthroughs on the horizon? What's the hottest news these days?

Every community is experiencing an explosion of autism and I don't think we're getting closer to understanding its cause or causes. In the end I suspect it will turn out to be a number of factors from genetic components to environmental factors to diet and immunizations. Tons of money is going into autism research because parents are demanding quality services for their children.

**The website for Early Intervention Program in New York State is [www.health.state.ny.us/community/infants\\_children/early\\_intervention/](http://www.health.state.ny.us/community/infants_children/early_intervention/). You can download *The Early Intervention Program-A Parent's Guide* which provides a thorough and understandable introduction to EIP.**

**Child Find is part of the Federal Individuals with Disabilities Education Act. The website is [www.childfindidea.org](http://www.childfindidea.org). There are many great developmental checklists available on the web. Try starting with [www.chp.syr.edu/Developmental\\_Checklists.html](http://www.chp.syr.edu/Developmental_Checklists.html).**

## [healthyfamiliesnewyork.org!](http://healthyfamiliesnewyork.org)

Healthy Families New York unveiled its new website on March 2, 2007 at 11 a.m.

The new site was designed to be a tool for families as well as program staff and others in the community, with pages like 13 tips for Growing Your Baby's Brain, developed by Dr. Kevin Karpowicz of Schenectady, and videos about SIDS, preventing Shaken Baby Syndrome and Traumatic Brain Injury. The new site encourages professional development of HFNY staff with resources and tools including a full catalog of the HFNY Resource Library at Prevent Child Abuse New York. The website welcomes the general public with a What's New section on the homepage, featuring HFNY program quarterly statistics, job openings and other current news about HFNY. Changing images accompany the HFNY motto, Supporting Parents Right From the Start, as it is translated into many of the languages spoken by HFNY participating families, so the site is designed to change to a fresh look each time it is visited!

The site is organized into these topic areas:

- **Resources—for staff and families**
- **Program Sites—information about each of the 29 programs and target areas**
- **Administration—a description of the HFNY Central Administration model and HFNY documents**
- **Training and Staff Development—describes services offered to programs by PCANY.**
- **Research and Evaluation—current papers, research links and HFNY research presentations**
- **MIS/Forms—MIS reports, manuals and HFNY forms, and a data submission port**

In the first month since the site was launched there were over 2,300 visitors. The job openings page alone was visited 230 times. And current and back issues of The Link can be viewed via two routes on the HFNY website: go to <http://healthyfamiliesnewyork.org> and click on Newsletter under the What's New heading, or click on Training and Staff Development, then click on The Link.

The new design was done by John Heck at the Center for Human Services Research, and the initial building of the web pages was done by the Professional Development Program of Rockefeller College.



John Heck, Center for Human Services Research

# Spotlight on South Bronx Healthy Families

**South Bronx Healthy Families**  
**Lisa White, Program Manager**  
**South Bronx Healthy Families**

On any given day as you walk down the Grand Concourse, a main street in the Bronx, you will be captivated by the people in the community. You will be struck by the greens, blues and reds that make up the many African fabrics draped onto the hips of the mostly West African women who are speaking French or various African languages. You will be introduced to women and men speaking Garifuna, the language of native Hondurans, as many of the elders in this society do not speak Spanish, the language of their conquerors. The corners are alive with people selling fruits and vegetables or items such as hats and flags representing the various countries represented in the community. The sounds of salsa, rap and reggae fill the air as cars quickly drive by. Welcome to the South Bronx!

South Bronx Healthy Families is located in the heart of this community at 1650 Selwyn Avenue, under the auspices of Bronx Lebanon Hospital Center—Department of Obstetrics and Gynecology. The program began in July 2001. We provide services to families residing in the 10457, 10458 and 10460 zip codes. Since inception we have served over 500 families and made over 6500 home visits. Participants hail from a variety of countries in Africa, the Caribbean, and Central and South America. Fifty percent of our participants are foreign born and speak many languages and dialects. With this vibrant multi-cultural group of people come various differences and challenges to practitioners serving the community. To address these challenges we have created non-traditional ways of engaging and retaining families that are culturally sensitive and reflect good practice. Families are identified and

referred from hospitals, clinics, WIC offices, pediatric offices, and other community based organizations.

When the program began we had a staff of 10, including the Program Director, Program Supervisor, Data Manager, two Family Assessment Workers and five Family Support Workers. We have since grown to add another Program Supervisor, two new Family Support Workers and a Clinical Consultant. Our staff is reflective of the community it serves and speaks English, Spanish, French and several African languages. Maintaining the energy of the staff is a main priority, as the work they do is often difficult and challenging. So we recognize their hard work and need for self care with our annual retreat. We spend the day rejuvenating our spirits and energy, while enhancing our leadership abilities. Without the commitment of the staff, the program would not be so successful and we would not be able to provide efficient and effective services to families.

We have made great accomplishments since we began. One of our graduates was chosen to represent Healthy Families America on the advisory committee of the Responsible Fatherhood Program of Circle of Parents. He will assist with providing leadership and oversight to home visiting programs, promoting responsible parenting among expectant and new fathers. And we have hired one of our first program participants who recently completed her bachelor's degree. She will serve as the new Data Manager. We continue to carry out the Pediatric Community Residency program with the Department of Pediatrics at Bronx Lebanon, through which pediatric residents visit the homes of program participants.

We held our first graduation in November

2006, with 12 families. The program staff highlighted the families' accomplishments and achievements, and each received an award. One graduate of the program gives back to SBHFN every year by organizing Christmas gift donations for the parents in the program. The impact of the program on him and his family is clearly remembered and strongly felt, and is expressed through his generosity. We have successfully implemented the Parenting Journey, a psycho-dynamic parenting group that meets four times a year and focuses on how the participants were parented and how their experiences affect them as parents. We also continue to hold our successful yearly events for program families, celebrating Mother's Day, Father's Day, Easter, Harvest time and Christmas.

One of our greatest success stories belongs to our first program participant. When we met Ms. G at Bronx Lebanon Hospital she had no food, her rent was past due and she had just given birth to her fourth child. Her husband had abandoned her, and being from Gambia in West Africa, seeking asylum in the US, she spoke very little English. An independent Muslim woman full of pride, she was ashamed of her circumstances and reluctant to accept services. As with many of our families with pressing needs, Ms. G found it difficult to focus on her child, but from the beginning she showed a strength and persistence that resonated with the every person on staff. Though she was taught to be respectful of government agencies and all people in a position of power, with her inner strength and perseverance and the guidance of her FSW, she obtained public assistance, a visa and a job. She taught herself English and is in the process of securing housing for her family. As her confidence grows and she resolves her challenges, she is able to really focus on her child.



Loew's Paradise Theatre on the Grand Concourse, the Bronx



*South Bronx Healthy Families Staff:*  
Top: Brian Smith, 2nd row, Cherise Davis, Nadine Johnson, Addy Senior  
Front row, Phyllis Bunter, Maria Beltran, Lisa White, Thema Maximo, Lynne Bermudez

# Grieving a Dream

Wendy Bender

Prevent Child Abuse New York

*A pregnant woman and her partner dream of three babies:*

*\* the perfect baby who rewards them with smiles and cooing*

*\* the impaired baby; the one that they worry about and who changes each day*

*\* and the ... real baby; the one they'll actually have*

*-after T. Berry Brazelton, M.D.*

All parents have dreams of their child's future. What will she be when she grows up? Who will he look like? How will she do in school? How will he affect my relationship with my partner? How will my family accept her? The list goes on and on. Over time these dreams erode as parents learn that this child is a human being with his own personality. He is not someone they can mold entirely; he has his own ways of expressing his needs and desires. When a family faces the fact that their child has a disability, they no longer have the luxury to adjust their dreams slowly. The impact of a disability can shatter those dreams.

How do a parents survive the new reality? How do they go on? How can they help their child, their other children, and themselves? How do they face the loss of the hoped-for "normal" child?

Ken Moses, Ph.D., a psychologist and a nationally renowned speaker, author, and clinician who has devoted himself to helping people deal with crisis, trauma and loss offers the following:

- The impairment, not the child, irreversibly spoils a parent's fundamental dreams.
- Recovering from such a loss depends on one's ability to separate from the lost dream, and to generate new, more attainable, dreams.
- Grieving is an unlearned, spontaneous, and self-sufficient process. It consists of states of feeling that provide the opportunity for self-examination, leading to both internal and external change.

When parents grieve, it is the loss of the dream they are grieving. This process always starts with the shock of the diagnosis and is usually followed by denial or disbelief that the information is correct. Later there are feelings of anxiety, anger, guilt, fear, and depression. These emotions can be very intense and scary to the family—and to us as home visitors. And families relive the process with every new test or stage of development their child goes through. We worry and wonder, what should we do? How should we respond to these uncomfortable feelings?

It is important to realize is that this process is normal, healthy and actually healing. Ken Moses offers a method to determine if we are doing ENUF to help.

<b>E—are we feeling and expressing</b>	<b>Empathy?</b>
<b>N—are we remaining</b>	<b>Non-Judgmental?</b>
<b>U—are we supporting the family</b>	<b>Unconditionally?</b>
<b>F—are we maintaining a focus on their Feelings?</b>	

If we are doing ENUF then we are doing our best. This fits so beautifully with our model and our role with families—to listen and not try to fix! One parent said, "It was a help every time a staff person reached out to ask how I was doing with it."

## Did You Know?

The Healthy Families New York website ([www.healthyfamiliesny.org](http://www.healthyfamiliesny.org)) has materials for parents in Spanish and English. These materials can be downloaded and printed right from the site and brought out on home visits.

The material on "Growing your Baby's Brain" (Puntos Para Desarrollar el Cerebro de su Bebé) is great for new parents and has 13 different handouts.

From the start page click on the FAMILIES window to check out these materials.

Tips for Shopping with Your Child

Winning Ways With Children When Eating Out

Preventing Shaken Baby Syndrome

*El Prevención de Síndrome Sacudido del Bebé*

Tips for Growing Your Baby's Brain

*Puntos Para Desarrollar el Cerebro de su Bebé*

PDF of Shaken Baby Syndrome Brochure

PDF of Reducing SIDS Risk For Your Baby Brochure

If you have a story to share with Victor Bernstein & The Link, email him at [vbernst@midway.uchicago.edu](mailto:vbernst@midway.uchicago.edu)

or Pam Balmer at [pbalmer@preventchild-abusenyc.org](mailto:pbalmer@preventchild-abusenyc.org).

To contribute, you don't have to write an article. Victor & Link staff will work with

## Further resources on parenting a disabled child

<http://www.ftnys.org/index.htm> **Families Together in NYS.** Resources, advocacy, moderated chats for parents, and more.

<http://www.familyvillage.wisc.edu/> **Family Village**—Home page for lots of resources on having disabilities.

[http://www.familyvillage.wisc.edu/frc\\_afrc.htm](http://www.familyvillage.wisc.edu/frc_afrc.htm) Specific resources for African-Americans with disabilities.

[http://www.familyvillage.wisc.edu/frc\\_fath.htm](http://www.familyvillage.wisc.edu/frc_fath.htm) Fatherhood resources.

*Parenting Your Complex Child: Become a Powerful Advocate for the Autistic, Down Syndrome, PDD, Bipolar, or Other Special-Needs Child* by Peggy Lou Morgan. An excellent book by a parent of a disabled boy; contains many insights, useful advice for documenting, working with professionals, and planning for the future.

<http://www.parentingyourcomplexchild.com/Index.html> Related website.

<http://www.autism.org/> Contains lots of articles, useful links, and essays by Temple Grandin.

*Developing Talents: Careers for Individuals with Asperger Syndrome and High-Functioning Autism*, book by Temple Grandin.

*A Parent's Guide to Special Education: Insider Advice on How to Navigate the System and Help Your Child Succeed*, book by Linda Wilmshurst.

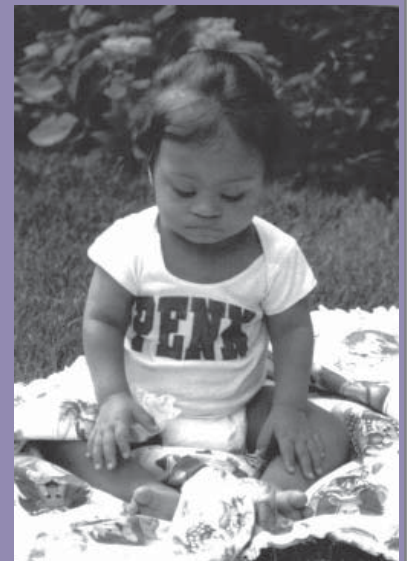
<http://www.makoa.org/index.htm> **disABILITY** Information and Resources. Extensive list of links of all types.

<http://www.vesid.nysed.gov/all/home.html> New York State Vocational and Educational Services for Individuals with Disabilities



# The Milky Way

**Rayza DeLaCruz-Stitt, RN, BSN, MSN**  
**Program Manager, Bushwick Bright Start**



*Noemi DeLaCruz -Stitt*

## Nursing a baby with Special Needs: Focus on Down Syndrome

When a baby is born with a disability, parents are called upon to adjust both to the usual changes brought by parenthood and to the additional challenges and changes of baby who is “different.” Parents will likely have questions about how to feed their baby with special needs. FSWs can help families make the best decisions by listening and helping them get accurate information. Babies with special needs benefit from the immunological protection, optimal nutrition, and early closeness with their mother provided by BREASTFEEDING.

Down Syndrome is among the most common disabilities caused by chromosomal abnormalities, and occurs when a baby is born with 47 chromosomes instead of the usual 46. FSWs can support families by providing information and specific tips that can increase success with BREASTFEEDING a baby with Down Syndrome.

### Reasons to promote BREASTFEEDING a baby with Down Syndrome (DS)

Immune system	Babies with DS have compromised Immune Systems	Breastmilk improves immunity
IQ	Babies with DS have lower IQs	Research demonstrates that breastfed babies had five or more IQ points than their formula fed counterparts
Otitis Media	Babies with DS are at increased risk for ear infections	Breastfeeding protects against ear infections
Celiac Disease	Babies with DS are at increased risk for Celiac Disease	Breastmilk has protective qualities for the intestinal tract.
Jaw Development	Babies with DS tend to have low muscle tone, tongue protrusion, and variations in jaw development	The mechanism of breastfeeding and use of facial/jaw muscles during suck and swallow improves jaw and facial muscle development
Speech	Babies with DS have more speech impediments and slower language development	Breastfeeding has been associated with improved speech development
Maternal closeness (PCI)	Moms of special needs babies are negotiating their maternal role as it relates to a “different” baby	Early breastfeeding promotes bonding

### A few special considerations when nursing the baby with Down Syndrome (DS)

Babies with DS will have a variety of developmental delays and need additional stimulation and support	Connect the family with services early	Refer to: Early Intervention Lactation Consultant (LC) La Leche League Counselor
Babies with DS have low muscle tone	Pay close attention to position of baby at breast and support the jaw.	Use a nursing pillow to reduce distance between mother and baby. Support the jaw with index finger.
Babies with DS are often sleepy	Wake baby if necessary and plan to feed frequently—about every two hours.	Use infant massage and other techniques to wake the baby before feedings. Work closely with physical therapist.
Babies with DS may grow differently from “typical” babies	Let the parent know that there are specialized growth charts to track weight and height	Inform parents that pre-and post feeding weights by a professional could be helpful to assess intake. Parents should avoid “overusing” this technique at home.
Babies with DS will benefit from early therapies—including Oral Motor Therapy	Early introduction of certain devices such as pacifiers could lead to nipple confusion (sucking confusion) if used inappropriately	Have the Speech Therapist work with an LC to strategize a therapeutic regime that avoids premature introduction of oral stimulation devices in the early weeks of nursing.

# Roving Reporter!



**Pam Balmer**  
**Prevent Child Abuse**

**Question: What do you like most about doing ASQs?**



*Jennifer Mudry-Rothenay, FSW, Ulster County Healthy Start: It's an easy way to get dads involved. Dads love ASQs!*



*Barbara Beichman, FSW, HealthyKids: My favorite part is doing all the activities before the ASQ is due and knowing the child can do a lot of the things ahead of time.*



*Luz Zapata, FSW, Ulster County Healthy Start: Fine motor skills. And I enjoy having the mother and the father there. If I know an ASQ is coming up I like to start trying the activities a visit or two ahead of time.*



*Faye Sperber, Supervisor, Bright Beginnings: Watching parents' reactions to what their child is doing.*



*Christy Hobbs, FSW, Early Advantages: Trying an activity for the first time and being just as excited as the parents are—being excited together!*



## Spring 2007



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