

## “Watching My Son Grow”

*An Illustrated Timeline from Birth to 3 Years Old*

By Joe Dimino

### ~ *Birth to 2 Months* ~

*During this time most children will lift head a little when lying on stomach, watch objects for a short time and make "noise in throat" sounds.*



The first real glimpse into my son's eyes was through the thick solution they gave to him shortly after birth. As this tiny newborn rested in my hands, I brimmed with a love I have never experienced before as I called his name and he tried like mad to open those new eyes of his to see his father's face and the voice he heard through the womb for many months. In retrospect, it seems an apt metaphor for my little Miles Alfonso Dimino born a click before 5 p.m. on the same day that Jim Morrison was born and John Lennon was shot - December 8 back in the year 2004.

On the heels of fervently falling in love with my wife, Carrie, we had only been together for 4-months when we conceived Miles. We both knew that we had fallen in love forever and were ecstatic to get married in July and welcome our first child into the world about 5 months thereafter. Things were moving at a fairly quick clip at that point. My wife had a son from a previous marriage, then 5-year old Zen, and was well-versed in raising a young one. I was spending those anxious months leading to Miles' birth hearing a load of advice, congratulations and stories about everyone else's experience in welcoming children into this world.

The birth of our boy was about as natural as it gets. Carrie was very conscious of her eating habits and overall health. She even went as far as not eating sushi due to unsafe mercury levels. Additionally, the birth was to be natural without the use of any drugs. All of this was achieved when Miles was born and we felt highly relieved that it went as well as we had planned. To this day, the birth of Miles is one of the most amazing days of my entire life.

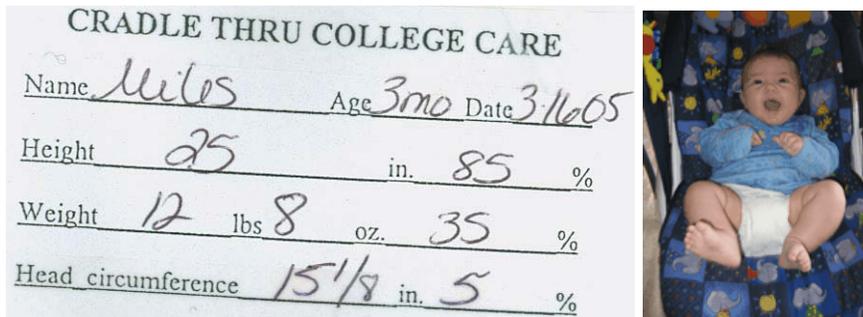
Shortly after Miles was born in the hospital, he was having a hard time latching on while trying to breastfeed. We were assured by several nurses and our delivery doctor that this can be a fairly routine thing to happen. In full retrospect, this would have to be the first sign that Miles was not going to fall into that category of a 'regular' baby.

As the months plodded forward and the excitement of fatherhood sank in, I began feeling the normal pangs of sleep deprivation and an extremely new life experience. And as time rolled forward, Miles began breastfeeding, but would not take a bottle at all. It simply wasn't a part of his equation. He would not and could not latch onto the bottle as an alternative to breastfeeding. This attempt to give him a bottle was only broached every once in a while. It was a sure sign of Miles' complete dependence on his mother for a very necessary ingredient of his growth and mental comfort. This was an issue that we deal with even to this day. He is very sensitive to odd textures and can easily gag.

*Actual milestones: After his first week he began latching on while breastfeeding.*

### ~ 3 to 8 Months ~

*During this time most children will lift head and chest when lying on stomach, show active body movement, sit with little support, roll from back to stomach and change object from hand to hand and from hand to mouth.*



In the early stages of development, the family was getting a regular monthly check-up from a Parents as Teachers coordinator. Over this time, we had a helpful case worker who would visit our home and give us solid child rearing advice. Even in the early stages of her visits, we would voice some concerns about his refusal to use a bottle. In addition, I know that Carrie had her suspicions about his overall development. I, on the other hand, was blissfully oblivious to any glitches regarding milestones. As time marched forward, we began to realize that Miles was going to have his own growth chart.

During routine visits and vaccination sessions with our pediatrician with some mild concerns we mentioned to Miles' doctor. Namely, by 7 months he wasn't rolling over. Our optimistic pediatrician would always assure us that everything was moving along just fine and some of these things simply take time. The doctor would always challenge the notion of the bell curve and say, *When he gets to college, no one is going to ask him when he started walking. Or, Each child develops at their own unique pace.* I cannot remember how many times we heard that throughout the first year and-a-half of Miles' short life up to that point.

Both our Parents as Teachers coordinator and pediatrician continued to tell us that it was way too soon to tell us if there was indeed something slow in Miles' development. They were genuinely unsure if there were any issues going on or not. Putting insurance concerns aside, I believe it's a very difficult task for a health professional to not only confirm, but disclose the fact that a child has developmental delays worthy of serious

concern. My wife always felt there was an “unspoken” philosophy to allow parents time to bond without worry.

*Actual milestones: He would start lifting his head some while on his stomach and sat on his own.*

**~ 9 to 17 Months ~**

*During this time most children will pull themselves to stand and may step with support, nod their head to signal "yes," pick things up with thumb and one finger, say two or three words, walk without support, speak and make their voice go up and down, drink from a cup held by someone and use four or five words.*

CRADLE THRU COLLEGE CARE  
Name Miles Age 5mo Date 3/8/06  
Height 30 in. 15 70 %  
Weight 21 lbs 7 90 %  
Head circumference 17 1/4 in. 34 %



Throughout the first 12 months of his life, I remained a determined optimist believing that everything would be fine. This was also a mantra that our families and friends would reiterate to both Carrie and I when Miles would be crawling around shortly after year one without any hint that he would be walking or talking would be in his future. Carrie knew better than everyone else that this point that something was not right in his development. I can see how alone she felt with this knowledge, but hope kept everyone sane. It still does.

I began taking all these issues into heavy consideration when we hit the 14<sup>th</sup> or 15<sup>th</sup> month and he was still not crawling. As the months kept slipping away and there were both no words and no walking, we began to hedge closer to the notion that things were hugely different from what I was expecting and some preventative steps were needed to take place. Our Parents as Teachers coordinator had mentioned that we should start to think about getting an in-home evaluation from First Steps to see if he qualified for their set of services.

*Actual milestones: He started to crawl and was beginning to pick some things up with his hands without precision.*

**~ 18 to 19th Month ~**

*During this time most children will walk without help, climb up and down on things, stand up and sit down without holding on, understand simple one-step directions, use more meaningful single words, gesture and use words together, hold out arms and legs while being dressed by others and point to objects they want.*



During the 19<sup>th</sup> month, we made an appointment with First Steps and had an evaluation done in the home. Ironically, this was the month that Miles finally started to walk. I remember that day as clear as anything that has happened in my life. We had stopped by Grandma Judy and Grandpa Austin’s home for our Sunday regular afternoon visit. Shortly after entering the home, I told Miles to *walk to gigi*. It happened. He quickly traversed about 10 paces over the floor and collapsed in a giggle into Grandma Judy’s arms. Carrie, Zen and I looked in slow motion silence at each other not quite believing what we had seen. Both Judy and Austin looked at us with that *what’s going on?* look and we said that this was the first time he had ever walked that far. We were all ecstatic and for a brief moment I looked into Miles’ happy eyes wondering if he waited all those months for some secret reason he will tell us some day far into the future.

During the initial First Steps evaluation, we told them that he had only recently started walking. We wanted to make certain that we conveyed to them that his balance and skill level was in its initial stages and didn’t want this to rule us out of getting much needed services. After a thorough evaluation, we found out several weeks later that he qualified for physical, occupational and speech therapies. It was both a relief and shock. Our fears had been validated.

*Actual milestones: He finally started walking on his own, but not too well. Also, he began using sign language more frequently to get things that he needed.*

**~ 20<sup>th</sup> Month – Testing Phase ~**



With a sense of relief and fear for the future, we were thrust into a world of “tests.” Genetics, MRI’s and pediatric specialists with an amazing range and we were firmly introduced to a medical community we had hoped never to know. At the same time, we were trying to figure out how to add 12 hours of therapy to our lives or how to keep our

jobs or how to go to soccer practice. Forget maintaining friendships or the long forgotten honeymoon, we were in full survival mode.

Leading up to these tests, Carrie had done extensive research on the Internet to find out more about Autism, Angelman's Syndrome and other developmental delays that seemed similar to Miles. Our first order was to go get blood and urine samples. Then, we were going to have to meet with an Orthopedic Surgeon to see what his recommendations were for Miles getting his gait and general walking straightened out. Finally, we were to have him sedated so that they could perform an MRI to see if he had brain tumors that might affect his language development and his difficulty with walking.

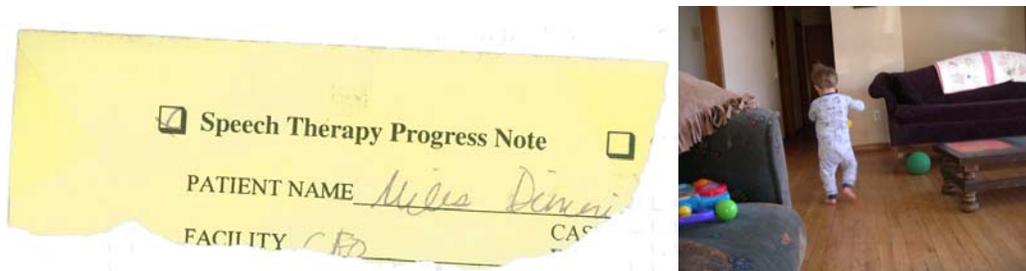
**~ 21<sup>st</sup> to 22<sup>nd</sup> Months – Results ~**



Several months later, after countless hours in waiting rooms we were told that he had no tumors and that all genetics could find as an extra long arm on his 15<sup>th</sup> chromosome. Since Miles has some facial features similar to children with Down's Syndrome, such as epanthanal folds, flat nasal bridge and lowered ears, the overall consensus was a glaw in his genetic code.

**~ Pre & Post 2 Years Old – Intense Therapy ~**

*During this time most children will give toys when asked, recognize a familiar picture and know if it is upside down, kick large ball, turn pages in a book (two or three at a time) and use two or three words together, such as "more juice".*



After six months of therapy with First Steps, we had our first full evaluation on where Miles was developmentally. The synopsis was that he had made some solid strides, but there was still a need for all three therapy services and more rigorous unification on the therapeutic front. Furthermore, he had been diagnosed with SID (sensory integration disorder). In essence, he was feeling everything in his world differently than us. He

needed our help and therapeutic assistance in coping with those difference and difficulties.

We had another solid six month stint and both Miles and the family were getting more comfortable with strangers in our home and the more permanent ritual of therapy in our daily lives. In fact, we made some good friends in several of the therapists that worked with Miles. The therapists were always very encouraged by our participation and zest to see Miles improve on a daily basis through the therapy that Carrie and I both believed in.

Over the course of these therapy sessions, our son Zen was very involved in some of the sessions to understand what Miles was doing and how he could help. Zen has been the best big brother ever under very stressful circumstances. Carrie and I couldn't laude Zen enough for the love, strength, courage and understanding of having to dole out the extreme amount of time and attention that Miles needs.

*Actual milestones: He began to recognize toys and interacting with them for the first time. Also, he was trying hard to begin kicking balls, and catching them.*

### ~ 2 ½ - 3 Years Old – More Therapy & Growth ~

DEA # 1004 CARONDELLET DRIVE, SUITE 910  
KANSAS CITY, MO 64114-4801  
(816) 842-6437

NAME Miles Dimens AGE  
ADDRESS DATE 4/7/08

RN-ILLEGAL IF NOT SAFETY BLUE BACKGROUND

**B:** Due to developmental delay it is medically necessary for Miles to have occupational + developmental therapy.

Refill times  Dispense as written

D. K. Kelly

SUBSTITUTION PERMITTED DISPENSE AS WRITTEN  
78PE0297311



During our one-year evaluation with First Steps, we were advised and accepted an invitation to include behavioral therapy as a part of our services. This was something that Carrie and I were wholly unformed about. We accepted and had one of the area's foremost experts in Autism therapy visit our home to evaluate what Miles' need level was going to be. About three minutes into her visit, she looked up at us and said, *Please don't get him tested for Autism. He simply doesn't have it.* Along with that relief of having an expert in the Autism spectrum tell us that, we were conversely concerned about what she witnessed during her visit. Aside from our parenting skills, this evaluator said that we would have a huge problem on our hands if we didn't act immediately and start modifying his behavior patters. At the end of a very thorough and effective visit, it was decided that we would spend 4 days a week both on-site and in the home giving Miles behavioral therapy services.

Both Carrie and I had no idea what to expect from behavioral therapy and were again on a heightened level of anxiety for what was to come. The fact that a trained therapist with

her experience level said he would be a big problem if behaviors weren't curbed, put a fright into our bones.

This is really when the rubber hit the road. To this day, the behavioral therapy has been a saving grace for the entire triumph of Miles flourishing in his daily life. These dedicated and patient behavioral therapists showed Miles and us how to temper the tempest of his sensory integration issues, lack of language, poor balance and general difficulty with attention span.

Again, Carrie and I were very involved in charting, giving him treats when he did a task successfully, giving high fives. Now, it was very clear that Miles had several elements that were a part of the Autism spectrum and that spectrum is rather large. So, from his inability to speak and sensory integration issues, he was firmly in a spectrum that simply became a 'special needs' label. If labels even apply in this emerging, mysterious and confusing condition.

Carrie and I were introduced to a host of parents and children that are in the Autism realm. It didn't take long for me to understand that the spectrum is vastly different from having autism. Sometimes when I would see tantrums that wouldn't stop or classic autism behaviors that were quite loud, I would peer over at Miles and study his reaction. Usually he would keep doing what he was doing, but stop at every once a while to peer over to see what was going on. It was a rather frightening and eye opening environment. Keep in mind, this was a facility that was in a strip mall and they charged regular paying folks almost \$4,000 a month for services. If it wasn't for the intervention of First Steps, I'm not sure what Carrie and I would have done.

As we barreled through his year of behavioral therapy, he was two-and-a-half and making great strides in all areas of his development. Over this year, he was finally exhibiting an interest in toys and general kid's stuff that held no interest to him during the first two years of his life. We were starting to see him break out of this thick shell of developmental delay and start exhibiting typical infant/kid behaviors we didn't see otherwise. The staff at the clinic loved Miles and again lauded him with praise for how well he picked up on concepts and tried so hard.

Those days of driving to the clinic and working rigorously with him for that one hour on site were some of the most important moments in his growth. He was out of the house, interacting with other kids, getting good therapy and giving the world his mix of romantic happiness. I was really blown away to see my him taking to learning and growing with such a verocity. Sometimes, I would see Miles leave thoughts of me being in the room and just thrive at what he was doing. It was during those moments that I would bite my beaming eyes and longing expectations and just enjoy the coolness that was taking place. But, he would always return pretty quickly and look up at me for a good, wide smile.

During the summer when Miles was two and therapy was really heating up, Carrie and I decided to establish a cathartic blog (<http://milesalfonsodiminotherapy.blogspot.com>) that would be a good forum for us to communicate what was going to family, friends and the world. We agreed that this would be an honest and frank forum to let those around us know exactly what Miles was going through and how we were coping. This blog was to

include frank testimonials, tips, photos, videos and any other bits that would better expose what kind of progress Miles was making. Overall, we wanted this to be a soothing mechanism to provide hope and healing for everyone that decided to stop by on a regular basis. Our ability to explain what was going on with Miles and why we simply weren't getting out seeing folks as much as we wanted to was made a bit clearer by us letting people in to get our honest take on our evolving lives with Miles.

I vividly remember this summer because it was going to be a huge chunk of time that First Steps was going to give us for behavioral therapy. Carrie and I were pretty focused on assisting Miles in a huge growth spurt both emotionally and physically. In addition to the ABA clinical therapy on-site and in-home, he was still getting occupational, speech and physical therapy services. This summer was interrupted quite a bit by a move that we were in the middle of trying to make. Our home had been on the meager housing market for about 19<sup>th</sup> months. Our primary aim for moving was to get into a better district for Miles. Our eyes were set on leaving South Kansas City for the more southern suburb of Belton, Missouri.

During July, the sale of our home was finalized and we scrambled to find a home of our own in Belton. The stars aligned and we were able to find the home we wanted and were going to get Miles ready to transition out of the First Steps services into Grace Early Childhood Center. This center was lauded in the Kansas City metro as one of the best facilities dealing with children that are in the Autism Spectrum and have developmental delays. We were ecstatic with this enormous life change that was finally going to afford us the opportunity to give Miles his own room. In addition, our break from a 2 bedroom ranch home to a multi-level home with much more room and a furnished basement was going to allow us a dedicated therapy space for Miles. In the old home, we had to endure the arduous task of converting our living room into a therapy room 12 times a week for every therapy session.

After the move and as the intensity of summer wined down, we began getting ready to go through the scary step of getting Miles into an actual school environment. The months leading up to our move and after our move were quite stressful in contemplating how life would be without an intense therapy schedule and transitioning into a public school program. Both Carrie and I had quite a bit to chew on as we moved into the last months of Miles' second year and his new journey into a big school environment.

### **~ 3 Years Old – Starting School ~**

*During this time most children will follow two- or three-phrase commands, sort objects by shape and color, imitate the actions of adults and playmates, and express a wide range of emotions.*



This was another time of intense research that Carrie did to figure out what an IEP (Individualized Education Program) was and how we would help the school district develop the best plan to meet Miles' needs. The other key component that was to take place after Miles turned three and transitioned into Grace Early Childhood was an official screening at Children's Mercy Hospital to get Miles an official diagnosis. This whole time, Miles was starting to get quite a bit taller and more mature in his overall look.

In his growth, Miles has continued to refine that rare ability to light up any room or public place he walks into. From his infectious smiles to waving hands, he melts every heart he comes across.

Leading up to our IEP meetings with Grace, we found ourselves against the wall because time was slipping away. Some administrative hurdles got in our way, and we had to rush in late November to get an IEP developed with the staff before Miles' third birthday on December 8<sup>th</sup>.

That was exactly what we wanted and got when his final IEP was drafted and set into stone. He was to receive speech, occupational and physical therapy, along with having a personalized para to ensure his safety. The other small nugget spoken of during this initial meeting was the possibility of Miles riding the bus on his own. Carrie and I were in such shock that Miles was even going to enter an environment that was hawked full time by either of us, that a bus seemed far out of the equation. This thought spooked both of us. The staff assured us that there had never been a student in their school's history that either refused riding a bus or got so terrified that they never rode the bus.

We nodded and agreed to take Miles to school for the first several weeks and give the bus a shot. Carrie, Zen and I took Miles into Grace on his first day and I felt quite numb by the enormity of my little boy actually going into a newer, more grown environment. That first day of tears was tough, but the culmination of our love, new move, getting into the school we wanted and seeing the growth our boy had made it all a cool experience.

When we picked Miles up that first day, he was in good spirits and had a solid first day. As the days turned into a week and a week turned into weeks, he was flourishing. They kept thinking that he was going to slip out of his honeymoon phase, but it simply wasn't in the cards. Our Miles boy was a little learner and he was thriving in his new

environment. The teachers loved having him in class and he was picking up quite adeptly to a variety of concepts.

Our next big school moment came when we took him reluctantly to the bus for the first time. I had it fixed in my brain that it wasn't likely going to work out and we were going to have to make new arrangements. The tears on that first day were floating as his little yellow bus shuttled his scared bones from grasp and around the corner into invisibility. It was another culmination of many nerves and *what if's* as Miles again took another brave, bold step into being an independent three-year old boy.

His transition into bus riding was much easier after the first week. In fact, it became the highlight of his whole day to do the rotating arms in sign language for the wheels on the bus. He loved the bus and his driver loved him. Everything was falling into step.

*Actual milestones: He started recognizing colors and shapes, along with following simple one-step commands. His ability to express a wide range of emotions, especially affection, continued to blossom. He starts to have an active interest in being with other children on a limited basis. This is more of an interest level to see what they are doing.*

### **~ 3 Years & 3 months – The Diagnosis ~**



During February, we finally got our appointment with the hospital to see if we couldn't get him a diagnosis. The first day was a whole battery of tests, evaluations and discussions with staff about Miles and how he was doing. At this point, Carrie and I were old pros at dealing with medical environments, a battery of questions and the general investigations into who Miles is. Miles was also becoming quite oblivious to this same line of testing and questioning. Again, either Carrie or I needed to be present in the room for testing to take place. We were always in the room during testing. Always at a safe distance, but we had to be there otherwise Miles wouldn't do much.

At the end of an intense 3 ½ hours of testing and evaluation, Carrie and I were unimpressed with this staff and their general grasp of his condition. We took it on the chin and had a follow-up session with just the two of us to discuss what label Miles was going to initially get in this long journey to ultimately find out what we had been waiting for these 3 long years. The final diagnosis was an *impulsive disorder*. In essence, they said Miles couldn't control himself and had a hard time dealing with impulses. They also ruled out Autism and spoke with us about medicating options. They recommended that we think it over and try a medication to see how it might work.

Leaving this meeting, Carrie and I were frustrated at what we saw as a rather harsh diagnosis. There's no real way to understand a creature like Miles after a 4-hour session and we have to always keep that in consideration.

On the drug/medication front, I accepted this as something we might try and Carrie thought it might be worthy of a try, as well. To put this to the real test, we asked his homeroom teacher what she thought and she refused the notion strongly. Her stance was that he is an avid learner that can have behaviors modified by an educational environment. We have seen his ability to modify his behaviors repeatedly at home and couldn't agree more. On the heels of his diagnosis, this was a great relief that we could live a drug-free existence.

**~ 3 Years, 8 months – Current Day ~**



Miles just finished his last day of summer school. Over his eight months of schooling and therapy, he continues to amaze and flourish. After his first six months, he had met a handful of IEP goals and was getting some new one's introduced to keep him evolving along a very progressive path. He has little friends in school and generally becomes more open to many things on a daily basis.

I have always thought the real issue with Miles is that he is behind other 3-year olds by about a year. Sure, there are some other distinct issues that are very different from other kids, but his maturation is going to be shorter. From a parenting perspective, it's almost sweeter. When little things like riding a bike and putting on his own shoe happen, they are victories that raise the hair on my neck. Since Miles entered my life, I have embraced the notion that it's no fun to rush the hand of time. I tend to see the glass half full and feel that I get a bit more time with my son to watch all of these little moments of life happen on a much slower scale. This is how I stay sane and keep the laughter rolling.

The key to watching a boy like Miles grow is that he is the happiest creature I know. His infectious personality and zest for small things like water slides and frozen yogurts has made my life enriched in ways that is hard to etch into the squiggles of ink on this page. I marvel each passing day to see how Miles will grow that much more. From the shoes he will outgrow to the scant new words that arrive here and there.

When you one has a child with special needs, you can have a tendency to break down or open the floodgates to what is amazing about life. I believe I have done the latter. I knew early on that I was going to embark on something that was going to be completely

opposite of what I envisioned parenthood. With that, I wouldn't change one moment I have lived. Through the pain, exhaustion and confusion, I decide each day to savor the joy that is within my family and this life. It's there .. and when an opportunity as I have arrives I can do nothing more than charge hard with a smile knowing that this is what I had and I'm going to damn well live it to the sweetest limits.

Each time Miles grows a bit more, I imaging those tiny eyes rising up for the first time seeing his dad peering down into a life that has made us understand that being alive is much, much more than walking, talking and bell curves.