

## **Broken Beaks and Wobbly Wings**

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*"Honey, you must give your children roots,  
but you also need to know when its time to give them their wings!"*

I often think of this with our children, and little by little I am trying to do that. I am learning to let go with my teenager who doesn't have FAS. I know I can trust him to make his own mistakes and be his own person and grow up the way he decides to grow up. I can let him learn to fly on his own. And I can allow him to become the person he is, not the person I want him to be. And that's okay. One of these days he will leave the nest and I will be so sad, grieving the leaving of my "baby." I know he will fly just fine, because he has good roots and strong wings. He will soar to heights I can only dream of.

I want my son with FAS to have the same chance for independence. But I know it will take longer before he is ready to leave the nest. After he leaves, when I can't be with him, he will need a support network to help him manage. Steve Neafcy describes what happened when he tried to leave the nest too soon:

*"My problem was not knowing I was FAE until age 43, I was expected to fly with the flock when I had a broken wing! Using this broken wing to try to glide with all my peers, was a living hell but the worst was failing and seeing the disappointment in Mom and Dads eyes."*

Our alcohol affected baby birds, like all other baby birds, want to leave the nest. Everyone (family, society, school, psychologists) seems to say we should give them their independence, even if they have disabilities. If we don't we are called "overprotective" and "hypervigilant" and accused of not allowing our children to enjoy the freedom that other kids have that our kids should have too. We should let them fly, so we're told.

Let's look at those wings. They LOOK normal. Hmmm. The wings aren't broken, they just didn't develop fully, they are stunted at baby bird size underneath all those feathers, and cannot support an adult bird in flight. But nobody realizes that until the grownup baby bird takes a flying leap out of the nest and lands on his little beak! Oops. Too late.

Now the wings really are broken. So we take baby bird back into the nest, but now we have a baby bird that's a grown up bird with a bent beak, wobbly wings, and a taste of the freedom of flying through the air. And he wants to taste that freedom again, so he flies again, even knowing he might crash again. So it goes.

Now, what if we can't take baby-boy-man-bird back into our nest? Or what if we can't keep him there now that he has been out of the nest? With broken wings and a bent beak, he will be the laughing stock of all the other birds and he will also be a candidate for becoming cat food. Yeah, there's cats out there, and dogs, and coyotes, just waiting for our little birdies who try to fly but can't.

I'm not going to explain who the predators are, you can figure that out. Vulnerability is a secondary disability, remember? So is arrested social development. So is impaired judgment, and lack of impulse control. Not conducive to flying freely in those tempting blue skies. When our birdies fly, they see lots of pavement and never a mountain top.

This message is NOT a slam to the moms and dads of birdies who have flown and crashed. They didn't know this was going to happen. They all tell me that if they had known then what they know now, they would not have cared if they were called "overprotective" or "codependent" or "hypervigilant" or "neurotic" or whatever else we've been called. They would be even MORE protective and vigilant.

This message is NOT meant to squelch any parents' hopes for their child's future. The failed flights that we see today are due to lack of adequate intervention in the early years, and also were fueled by false hopes fed to us by the disabilities community and others who, meaning well, have pushed independence and inclusion and mainstream as though our kids could just sail right along with their peers if we only "let go."

Maybe some of the little ones really will be able to fly when they are older. The chances for independence (in living and employment) for kids with FAS/E growing up in the 80's is only 10% (according to Streissguth), but I'm sure that figure will increase as we learn more about effective intervention strategies for FAS/E. We also need to work on selling the importance of these interventions to the "system" so that our birdies get the support they need to fly, even if it means flying with them to support them when they start to veer off course or take a dip too low.

Even if only 10% of those birdies with bent beaks & wobbly wings are able to fly, that means that one in ten might be able to make it. We know that the range of alcohol effects is wide, and each child has unique abilities and disabilities. We know that there are many problems that are inherent with the syndrome. But we also know that a few can function somewhat independently. Parents can draw from the wisdom of those who have traveled this path before, but in the end they will need to rely on their own judgment to determine if and when that time to fly may come. Every child has the right to earn whatever degree of independence he or she is capable of without jeopardizing the loss of that independence. The child also has a right to safety and quality of life. It is crucial to be able to recognize the limitations without losing hope of fulfilling the child's potential, in order to find the balance that offers the greatest chance for success.

We need to be realistic in the hope we offer to younger families. It is not fair to encourage parents to have unrealistic expectations for the future of their children. Hope that is built on false ideas today will be crushed mercilessly in failed attempts to fly tomorrow. I think it is healthier to give

parents a realistic hope mixed with warnings of the dangers inherent in FAS/E that might be a little hard to swallow now, but in the end a lot of pain and grief can be avoided for families. I was fortunate enough to have good information available to me as during Johnny's adolescent years, and I had the foresight, even before Streissguth's reports were released, to know that Johnny would never be able to fly on his own. So I prepared him for this, starting way back when he would talk about "when I grow up, I want to drive (marry, be a daddy, become a famous drummer in a band that makes millions of dollars, etc.)"

Now, I was careful enough to not burst his bubbles completely, but I also loved him enough to not let him believe that all those dreams would come true. Instead of taking away his dreams, I changed his dreams a little. He can learn to drive (way out in the middle of nowhere), and marry (if he ever finds someone who will have him), or stay single (no shame in that, I learned), be a daddy (to a puppy or two), make lots of money (70% of minimum wage IS a lot of money in John's eyes) and become a famous drummer (almost everyone in Tucson has seen his video or has seen him on TV or in the newspaper, so he feels famous).

Does he want to fly? Of course he does! But he knows his abilities and his limitations. I remind him of both as often as I need to in order to keep him balanced between reality and dreams. He accepts his disability, with moments of frustration occasionally expressed with verbal outbursts that are not unlike those of my non-disabled son (non-abusive and quite appropriate). For every moment of frustration with not being able to fly, John has several moments of appreciation, joy, excitement, expectation, hope, and happiness about living his life in this nest.

And I take him flying with me as often as I can. No "real" independence is in John's future, but he feels free at times and he feels happy most of the time. He is safe and secure within the limitations of the home nest, and accepts the restrictions of flying only when he has his wing supports on (mom, brother, mentor). This boy-man-birdie has a straight beak and a strong body and a bright mind and a happy spirit. The wobbly wings don't really bother him that much, because they just aren't an issue. But we never forget for a moment that those wings will not carry him farther than he can fall.

My job as mama bird was never to prepare John to fly off on his own. My job has been to ensure that the proper supports are in place so John never has to experience the pain of hitting that pavement or the fear of being confronted by predators. My job is not done yet, so I'm keeping this little bird right here under my wings, that have become stretched and strong over the years of being "overprotective."

"Somewhere over the rainbow, bluebirds fly... Birds fly over the rainbow, why then oh why can't I?" Let's find some rainbows! And let's help our kids fly, but never, never alone. I made a promise to John once. He came to me with such anxiety and fear. He said, "Mom, I know I can't behave when I'm on my own, and that I need you there to remind me of what I forget. Mom, I'm afraid that someday when you aren't here to be with me, that I won't be able to help myself, and I will do something bad and get in trouble, and I will go to jail. Mom, I don't want to go to jail. I think I would be better off dead than going to jail." I made a promise to John that day. I said, "John, I will not let you go to jail. I will do everything in my power to keep you safe and to protect you from your disability. You know you need someone to be with you all the time, every minute, in order to stay safe." "Yes, Mom, I know." So we work together to educate the "system" and to look for alternate means of support, because these old wings aren't going to hold up forever.

Some birdies don't need too much support, and some can actually fly with minimal assistance, but there has to be some kind of safety net in place just in case. Hurray for the few who can make it and thrive. May they see all the rainbows and mountain tops they long for. Remember though, this is the exception, not the rule. I'm not being pessimistic, just realistic. I feel fortunate in that it is relatively easy for me to provide John with wing supports (for now, anyway). Some birdies are heavier, so to speak, and need stronger supports than parents can offer.

Sometimes the community is not willing or able to help with those supports. I want to reach out to some of those parents and offer help. That is so hard to do so far away. That is why I do everything I can to gather twigs of information and tips on building stronger nests. Let's all work together to strengthen our communities so we can take our kids over the rainbows and up to the mountain tops. Let's work on making our own nests secure. And let's be careful about false hope that is given as misguided encouragement that could result in parents pushing the birdies out without safety supports.

During the early years of my parenting John, there was not much information available on what to expect for his future. I had to wing it, so to speak, and had to rely on basic good parenting and my own maternal instincts. There is so much more known today about what intervention strategies work best. Even though we can't change the primary disabilities of impaired neurological function that stunt social development, we can learn how to parent in ways that minimize some of the more avoidable pitfalls, and increase the chances of success in school and on the job, with relationships and with life in general. We might not be able to strengthen those wings, but we can strengthen the safety nets, and we can encourage our young to fly tandem, with mentors and coaches, who can accompany them as they discover all that life's expansive horizons have to offer.



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