

HERE'S WHAT YOU CAN DO

A Teenagers View of Joy, Laughter and Hope While Living in a Family with 2 Brothers Affected By Autism

### **KNOW THIS FIRST**

Just so you'll know up front – I know it's hard. I know that having children or brothers or sisters affected by autism isn't easy. I have 2 little brothers affected by autism and I get to experience every day – the SAME EXACT things you do. Don't think for one minute – just because of the way I've learned to approach our family situation – that I don't GET IT. I do – I KNOW what you're going through, what you have to endure and the feelings that you are overlooked or don't get the attention you need or deserve.

I am just like you.

But I also know there are some things you can do that will help you – to use my families motto – "Thrive In Chaos." Right now I am going to share with you a few simple principles that will help you do just that.

# WHAT I'LL COVER

My name is Alek Jetsel, an I'm a 17 year old young man. The things I'll share with you today aren't things you'll typically hear from a 17 year old boy. I'll be sharing some things and some ways I've learned to adjust to living in a non-typical family.

I'll also share with you some personal experiences that have lead me to take on a certain attitude that ultimately leads me to happiness – much more happiness – than if I let the situation define me – instead of defining the situation for myself.

The outline – and attitude – I'll be sharing with you today is what I'll call the 4 A's. Those 4 A's are Acceptance, Affection, Appreciation and Availability.

Let's cover each one in more detail now.

### FIRST: ACCEPTANCE

The best example I can think of when it comes to acceptance is when I was in t-ball back when I was 5 or 6 years old. We had two coaches. The head coach was a "yeller" that would pitch a big fit every time there was a mistake made. A kid would drop a ball and old coach Buzz would scream at the top of his

lungs, "C'MON, CATCH THE BALL, IT WAS RIGHT IN YOUR GLOVE!" Then the poor kid would hang his head because he felt he had disappointed coach Buzz.

Then the backup coach would pipe up and say, "That's all right buddy, you'll catch the next one – you're doing fine – you can do it." And I would see the kid's head rise a little bit and his body would straighten up and he'd get back to ready for the next time.

### **Two Lessons Learned**

Two things I noticed. First, coach Buzz's son typically didn't get the "pick me up" from the assistant coach like the other kids because his Dad was on him more than the others. Coach Buzz's son became so scared that he would DROP the ball... that it started to affect his performance and his happiness and the result was that it made him a weaker player resulting in MORE dropped balls.

And second, I started to realize that I – and all the other kids that the assistant coach was pumping up – were unafraid to try because we knew we'd get better and maybe even like the assistant coach said, "You'll catch the next one – you're doing fine – you can do it."

Then something REALLY got my attention. Coach Buzz would reward us after we WON games, but the assistant coach – even though coach Buzz didn't want him to – would reward us after we LOST games. For YEARS I wondered why until I was finally able to ask him and he said, "I didn't want to reward you because you WON, I wanted to reward you because you TRIED. I accepted that you guys weren't perfect, but I wanted you to know I appreciated how hard you were working. Not everybody wins all the time. But if you TRY your hardest all the time, you are a winner."

He simply ACCEPTED us the way we were and expressed that through his actions.

# Performance Based Acceptance Is Very Risky

We need to learn to accept people the way they are and not base our acceptance on performance.

Regardless of their performance we need to hold ALL people with HIGH REGARD – not based on performance, not based on EVEN EFFORT, but based on the fact that they are human beings and we are ALL worthy of love and compassion.

Now, don't get me wrong: Bad behavior is not acceptable – but we shouldn't make people feel like LESS than human beings no matter HOW they act.

## **Change Your Attitude - Change Your Life**

Another form of ACCEPTANCE is acceptance of our situations. By accepting the situation we are in we can more easily put ourselves in a position to learn and grow. I remember as we first learned my two little brothers were affected by autism we did some research and came to see a commonality on blogs and websites and those kinds of things. Although they were designed to be helpful and we're sure they did that for some, they were mostly sad and a bit hurtful for us to read – and possibly other readers as well. All they did was make us think MORE about the gravity of what we were up against. There didn't seem to be much positive stuff out there for us.

Well, we had things happen all the time that were funny and zany and silly so we decided to start our own blog and only post positive and uplifting stuff. Kind of like the assistant coach who was always saying, "You can do it, you can do it" and eventually, we did. We decided that maybe someone out there needed that type of uplifting – because we sure knew we did.

And guess what? It did. We went from being embarrassed when they did wacky stuff in public, to starting to laugh and say, "Wow, that's going to be funny when we post it." We found ourselves starting to look for – and focus on – things that were funny and would make us laugh and bring us JOY so that we could post them for others. And we found it.

Obviously, there is still struggle and it's still hard, but because we go in to it with the right attitude, we are more able to learn and gain. And it's made us better, stronger, happier family.

## Own It

Another point when it comes to acceptance is to NOT be afraid to share their – sometimes wacky – lives with others. Initially, I was a bit hesitant to bring friends over to hang out because you never know what my brothers would do. But after taking a chance and showing my acceptance of them to my friends – and not being embarrassed, I found that my friends started to take on my attitude towards them as well. It wasn't necessary for my friends to feel a bit weird around them because I wouldn't. If they said or did something wacky, I played along as I always did and my friends got a kick out of it.

I'll never forget the time I had some friends over to play Rock-Band on the WII. I was on guitar, another friend was on drums, another friend was on keyboard, and my two little brothers were singing at the top of their lungs, belting out – rather badly I might add – "The Eye of the Tiger."

To my surprise, my friends were "cracking up" loving their wacky rendition of the famous 80's ballad. Because I was enjoying them, my friends were enjoying them. They have no fear of rejection, so they were right in the middle of all the action.

Another time, I was about to leave for a date when one of my brothers who was sitting on the couch said, "Hey, Alek, is that your girlfriend?" I started laughing, my little brother started laughing and my date couldn't help but laugh as well.

#### You Determine What You Get

Here's what I've learned. Having siblings affected by autism CAN be embarrassing OR it can be pretty funny. But YOU get to choose which it is. Have fun with it and it can be fun.

The best part of all is that as I give them acceptance and love, they return that same love and give it back more than you can imagine. They KNOW I care and love them because they can feel it and they can't wait to show me that same kind of love.

This was really made evident to me one day as we were all leaving the dentist. I had gone and helped my Mom with them while they were having some teeth work done and when we were done, my Mom asked all the kids to get in her car to go home. Since I had come from school I had my car there and my two little brothers started begging my Mom to let ME drive them home. They were SO excited when she said yes and it just made my heart melt a bit to see them experiencing so much happiness.

And THAT'S a REAL REWARD. They love and accept ME – and I feel it – because I love and accept them. Cool, huh?

So, now that we've covered the importance of ACCEPTANCE, let's move to...

#### **SECOND: AFFECTION**

One of the ways I see affection is because my parents "play" or sometimes "tease" me. As a for instance, last season during summer two-a-days for high school football, I go out onto the field for the first day with helmets and start to get some weird looks. Initially, I wondered if it was the fact that I waited until I was a senior to start playing football but soon forgot about what was happening as I trained and did all the drills.

Then I went over to take a water-break and pulled my helmet off and I'm sitting on one knee watching the other drills go on and I look down and what-do-you-know. There's a sticker on the side of my helmet that appears to be a stick figure of a man holding a football under one arm and making a muscle with the other. Holy Crap – you know the ones, right? The ones you'll sometimes see on the back of minivans where they display all the kids in the family? Yep – THAT kind.

I immediately thought to myself, "That rat, my Dad, put a sticker on my helmet to mess with me." So I looked at a few of the other players next to me and said, "Did you guys see this? When were you going to tell me that I had a "goofy" stick-figure on the side of my helmet?" They all looked at me and one of them said, "We THOUGHT that was sorta weird that you put that on there. Why did you do that?"

I said, "IT WAS MY DAD, HE'S GOOFING WITH ME." They all laughed as I peeled the sticker off.

Then when I got home I asked my Dad, "Did you put that sticker on my helmet?" He threw his head back in laughter, walked quickly towards me and gave me a big-ole bear hug – trying to pin down my arms so I couldn't retaliate or get away. "I'm sorry, I couldn't help myself" he said, as he continued to laugh and squeeze me tighter to protect himself from my wrath.

And that's one of many ways I notice he shows me affection. He shows me he cares by "playing" with me and laughing WITH me whenever he gets a chance.

## **Have Fun With It**

I've also seen the ways affection is displayed and its incredible value to my little brothers affected by autism by my OTHER younger brother Zak. Zak is the "Master of Affection." He loves kids more than anyone I've ever seen and he LOVES our 2 younger brothers affected by autism – and he SHOWS it.

He always takes the time to play with them no matter where we are. He climbs around with them at Burger King Play-Land – remember, he's 15 – and at the park and anywhere we go he makes SURE they have fun. He'll even do that with his even younger twin brother and sister. No kidding, he'll do goo-goo-gaa-gaa faces at them to make them smile no matter who is watching. He doesn't care what you think – he's gonna show them he cares. He's a great example of how powerful it can be when you CARE enough to show people you care no matter what's going on.

But one of the funniest – and most powerful – moments I ever saw was one time when he was mowing the back yard, which can be tedious to begin with, and he STILL took the time to play with our brothers

affected by autism. So as Zak was mowing the backyard they decided there was some fun to be had. They created a game that consisted of running across in front of Zak – not too close, of course – as he rolled by. Zak smiled and you could see he decided that instead of being bothered by them – which is easy to do because you're trying to get the job done – he was more than happy to participate in their fun and took the game to a new level.

## A Lawn Mowing Injury

Occasionally, he would quickly – and rather stealthily – stop the lawnmower, start yelling and swinging his arms like a crazy man and start to chase the two all over the backyard. It was fun to watch. The lawn was getting mowed AND there was giggling and running and laughter galore. Then it happened:

They found some tennis balls and hid them behind their backs. As the next occasion presented itself, Zak stopped the lawnmower, starting yelling and swinging his arms like a crazy man and started the chase. They quickly pulled the weapons from behind their backs and fired – FIRED! – the tennis balls in Zak's direction. Direct Hit! Zak doubled over in pain – and LAUGHTER.

That's right, you guessed it. One of the tennis balls hit Zak right in the – well, here's what Zak yelped through laughter. "You hit me right in the IGLESIAS!" For those of you that don't speak "boyish" – that's "the NETHER REGIONS." OUCH!

He could have been bitter and screamed at them to "get out of the way" or yelled at them because they were slowing down his progress, but he didn't. He SHOWED them he cared by showing them the affection they deserved. What a GREAT example of what we should all do, huh?

Okay, so now that we've covered ACCEPTANCE, and AFFECTION, let's cover...

# **THIRD: APPRECIATION**

It's amazing how simple this concept can be. It's also amazing how FAR a simple little bit of appreciation can go. Here are a few examples of how my parents do it.

### **Running On a Full Tank**

One morning I went out and got in my car to go to school and my seat was a bit lower than normal and I was a little confused – UNTIL – I started the car and the gas tank had gone from empty, the night before, to being full. My Dad, after I had gone to bed had taken my car out for a ride and filled my tank up. Now, that may not seem like much to you, but to a 17 year-old with no job – that is HUGE. He didn't have to say a word. He made me feel loved and appreciated and I made sure when I saw him I thanked him and appreciated him right back.

Or my Mom, when I walk in from a hard day at school, simply asking me, "How was your day? Can I get you anything – a snack or a drink of ice-cold water?" Sounds simple, I know – but the way it makes me feel is that they appreciate me and are willing to help me.

Different little acts like that show me they care and appreciate me – and as I get that from them I forward that appreciation to my little brothers and incidentally – it breeds that kind of attitude towards others.

## **Drawing Strength From Appreciation**

Erik (my 12 year-old brother affected by autism) loves to draw. But one of the ways he shows you that you are special is that he'll draw FOR YOU. I'll never forget the time he drew all the superheroes he could think of and we started naming them off together. There was Spiderman and Superman and The Flash and Iron Man and The Hulk – and he's a pretty good artist so it's easy to tell who is who. But then I saw a super hero I had never seen – a blond, strikingly handsome (giggle) fellow with a big A on his chest.

After a few wrong guesses – Americaman? NO – Aquaman? NO – Arithmaticman? NO. I asked, "Well, who is that?" When he said, "Super Alek" I was a bit overwhelmed. "Here, you have it" he said. Well, as you can imagine, it's a prized possession of mine.

He also writes us different notes that have to be de-coded, because he doesn't always quite get the idea. Like the one time where he wrote me a note that said:

Dear Erik

Ricky and me are playing. I love you.

Love Alek

Keep in mind, he (Erik) is the one writing to me (Alek) – but I GET IT – I KNOW what he means. I get that he wants to share his fun with me and express that he loves me. And as you can imagine, I ALWAYS tell him how great it is and thanks for thinking of me. AND he always smiles – ALWAYS.

# **Rubbed The Right Way**

My parent's appreciation rubs off on me, my appreciation rubs off on my brothers and my little sister, and then it all cycles back around over and over. It's a vicious cycle, huh? All the appreciation confirms we are all loved and admired in our family. It's a great feeling.

One of the ways this impacted me most was one time when I caught my father. Now, I think he may be a bit embarrassed by this but it's too good to leave out – and it's a way to get him back for putting that goofy sticker on my football helmet – so here goes:

Last summer my parents sent me and my younger brother Zak to Utah for an event with a bunch of kids our age and needless to say, IT WAS AWESOME. So after we got back I took a piece of paper and folded it in half and on the outside I wrote: THANKS. And on the inside I wrote:

Mom and Dad,

I appreciate ya'll so much. Being at that event this year was a really good experience. Thanks for letting me go. I know money doesn't grow on trees and I understand the sacrifice you make to let us be at these kinds of events.

Thank you.

Alek - AKA "Your Eldest"

Then I set it on the kitchen counter. When my Dad came home from work later that day I happened to secretly see him pick it up and read it. Then he read it and read it and read it and I was thinking, "How long does it take? It's a short note."

## He Calls It Eye-Sweat. Pffffft!

Then I realized he was choking up and I'm sure he'll never admit it but I would swear I saw his eyes welling up. Then he closed it and starting walking fast towards my Mom and I heard him say, "Shelly, did you see this?"

Keep in mind, this was just a quick little thank you note, but I'll bet you \$100 that if you were to stop him and ask him where that note was – he could tell you exactly. He may even carry it with him. I KNOW it made a big impact on him – more than I could have thought – or ever imagined.

You see, it doesn't have to be a big huge thing. Just saying "I appreciate you" can change the way someone feels about you – and themselves. And I'll guarantee you this. If you are looking for ways to show people appreciation, you'll find ways – AND – you'll be focusing on the good in people and it will get harder to see the bad.

So now that we've covered ACCEPTANCE, AFFECTION, and APPRECIATION, let's move to the final "A" and that is AVAILABILITY.

## **FOURTH: AVAILABILITY**

It's no secret that kids and children spell love by using the letters T. I. M. E. It can really make a difference in others lives when we spend time with them. TIME is one of the greatest ways to make people feel loved.

## **Quality or Quantity? Both.**

Now I know that a lot of people (typically adults) try to claim "Quality Time" is better than "Quantity Time." Coming from a teenager's perspective, I'm not so sure I agree. Sure going down to Utah with my father and brother for the weekend to watch LeMans Racecars was awesome – and I have great memories of that. THAT was some QUALITY time – I still have the posters to prove it. But I still think – and definitely feel like – just spending **simple time** with us is JUST as necessary and valuable.

I can remember when we first moved to Boise Idaho, from Dallas my Dad would take us (just me and my brother Zak) thrift store shopping every Saturday morning. We'd walk around looking at books and bikes

and raggedy footballs and toys and just "goof around" with each other. Zak would hide behind racks of books and then when my Dad was scanning them he'd scream, "BOO!" and my Dad would jump out of his skin. Or we'd try on hideous clothes or shoes or tricycle race down an isle.

The truth is... we rarely bought anything. But the fun we had just spending time together – doing nothing – created some great memories.

Along with Frisbee and playing catch with a football in the street in front of our house, or jumping on the trampoline with us – well, not so much anymore (his old knees and back can't take it anymore) but both my Mom and my Dad always make time just to be with us.

#### Be There.

I think the key to this is that when they're there... THEY ARE THERE. They aren't reading books or surfing the internet or talking on the phone – they are paying attention to and talking to us – sometimes even when we don't WANT to talk – ESPECIALLY when we don't want to talk.

My Dad once told me that he can tell when any of us has done something we shouldn't have because we aren't willing to just goof around and talk to him. And when he notices THAT, he won't let us alone. Sometimes when you DON'T WANT to talk, you just DON'T WANT TO TALK. For my parents, that seems to be a signal that we NEED to talk.

And now that I think about it – IT WORKS! But ONLY because they have taken the time to really get to know us by spending so much T I M E with us.

# Going For a Drive.

I've also noticed that when I take TIME just to be goofy with my brothers affected by autism, they feel loved. I remember one time we all piled in the car, rolled down all the windows, turned up the music, and cruised through my neighborhood – all singing as loud as we could – BADLY, I might add.

But Erik and Ricky were in heaven. They smiled from ear-to-ear and as soon as we got back started in with, "AGAIN!" Simply T I M E, doing simple stuff, shows them we love them.

#### **BURN THE 4 "A's" IN TO YOU BRAIN**

So there you have it. The 4 "A's" - ACCEPTANCE, AFFECTION, APPRECIATION and AVAILABILITY.

As I've seen these 4 "A's" modeled, it has been mirrored over in my attitude and dealings with other people, especially my brothers Erik and Ricky. By **being accepted** and then ACCEPTING my brothers and their situation; by **seeing affection** and then SHOWING AFFECTION; by feeling appreciated and then SHOWING APPRECIATION; and by having others available to me and then BEING AVAILABLE for others this "burden" as some may see it, has translated into a happy and joyful learning experience in my life.

By using these "tactics" with your own children or friends or relatives, or with just about anyone we have a relationship with, what may appear as hard or miserable situations, will emerge as experiences that better us and that make us happier and that we can learn from. And THAT'S what is most important – to learn and grow.

# Here's A Challenge – And A Promise.

I challenge you to implement these principles in your life and I am comfortable promising you that if you do, you'll improve your relationship with others – and YOURSELF. You'll be happier, feel more fulfilled and be ready to take on any and all challenges that you'll face.

You can do it – you are capable.

Alek



Alek is a typical 17 year-old. Texting, facebooking, high-school football and rugby, you know – all the typical stuff. One big difference though – Alek is the oldest of 6 kids, two of them affected by Autism. At 17, Alek has already become a highly sought after speaker and has motivated groups from 10 to 600 people. Contact Alek at ajetsel@gmail.com