

# GOD'S PURPOSE IN MY CHILD'S DISABILITY

### Parenting from the Heart

The importance of self-esteem

### **My Best Friend Fela**

She didn't give up

### **CONTENTS**

### FROM THE **EDITOR**

God's Purpose in My Child	's
Disability	

3

L

h

8

0

10

12

Interacting with People with Special Needs The basics

**Parenting from the Heart** The importance of self-esteem

Don't Be Afraid to Hire People with Disabilities Learning from one another has its henefits

Bipolar Disorder and Your Job

**My Best Friend Fela** She didn't give up

**Notable Quotes** Life with disability

Issue Editor

Design

Contact Us: Email Website Motivated Vol 7, Issue 11 Christina Lane

awexdesign

motivated@motivatedmagazine.com www.motivatedmagazine.com

Copyright © 2016 by Motivated, all rights reserved

I am grandma to two children with special needs: One grandson, now 15 years old, was diagnosed with Neurofibromatosis (NF), and another grandson, nearly 10 years old, has High Functioning Autism (HFA). Just as these disabilities are completely different, these two boys—including their personalities, talents, and needs—are unique.

The special needs journey is never an easy one. It is fraught with challenges for the caregivers, and it can be tremendously difficult for those with disabilities also. They often feel misunderstood, and can face labeling or bullying, which can result in a loss of self-esteem.

One of the best things we can do for anyone with a disability—physical, neurological, intellectual, or otherwise is to accept, support, and encourage them. Having a caring and understanding parent, family member, teacher, mentor, or employer can make a big difference in the lives of those who face special challenges.

The articles in this issue of *Motivated* remind us to respect and see the potential in those with special needs. When we do, they will blossom, and may surprise us by exceeding our wildest expectations, like the many—both famous and less-known—who defied the odds and went on to lead successful and productive lives despite, and because of their disabilities.

My two amazing grandsons are proof of this. They already contribute to our world in a special and unique way, and I don't doubt that they will continue to amaze us. I am so proud of them.

Christina Lane For *Motivated* 

# God's Purpose in My Child's Disability

By Sandra Peoples, adapted



My sister has Down syndrome, so when our family goes out to eat or out anywhere, people notice us. Sometimes they stare. Sometimes they smile. Sometimes they just look away. Young children may ask questions or point. It becomes so common that we don't even notice it anymore.

But our son James has autism, which can't really be seen. Usually, it's heard. If we go to the grocery store and he screeches, people look. If we're at the park and he jumps and flaps, people notice. Depending on how loud he is or where we are, we sometimes get dirty looks or exasperated sighs in our direction. We've even gotten a few questions. Last month James and I sat down at a potluck in a community center. The lady I sat by gestured to James and asked, "Is he going to grow out of that?" I wasn't sure what she meant. "His autism? Will he grow out of his autism?" "Yes," she answered. Then she followed up with, "What did you do when you were pregnant to make him that way?" In another conversation I had with a mom at my older son's theater rehearsal, I was asked "Did you eat a lot of tuna when you were pregnant? I hear that's what causes those problems."

I don't always know how to respond gracefully to such questions.

Many parents of special-needs children struggle with this. We wonder if it's our fault. If we're being punished by God for something we did or didn't do.

Amy Julia Becker, who wrote *Good* and *Perfect Gift* about the birth of her daughter with Down syndrome, says, "Penny is neither a rebuke nor a reward. She is a child, not a product of sin, or of biological happenstance, or of any lesson we needed to learn. No. This happened that the glory of God might be revealed."

So in response to the question "What did you do to make him like that?" my answer is, "His life is a testimony of the power of God. He glorifies God. In his autism. In his struggles. In his flaps and screeches. In his triumphs and successes. When he tries a new food and learns to use the bathroom. When he is the reason our community now has a special-needs program."

It's not about me (or the tuna I ate or didn't eat). It's not even about James. It's about how everything in creation can bring God glory.

Interacting with People with Special Needs

**The Basics** 

By Shawn Henry, adapted

S ome people are uncomfortable talking with people with special needs. One reason for this can be that they feel sorry for them, and assume that they are bitter about their disabilities. This is untrue in many cases. People with disabilities often feel that their lives are enriched by their experiences, and even if given the chance to erase their disability would choose not to.

Another reason that some people are uncomfortable around people with disabilities is that they're afraid that they will "say the wrong thing." However, that's not a big deal to most people with disabilities. What's important is that you respect them, and see beyond their disability.

Many people wonder about appropriate

terminology. Is it disability, impairment, or handicap? When you're working with someone, you can ask what terminology they prefer, and when speaking in public, or writing, you'll need to do a little research to ensure that you use what is widely-accepted, and avoid potentially offensive vocabulary.

The most important thing to know when interacting with people with disabilities is that they are people. Once you get to know a couple of people with disabilities personally, all sorts of incorrect assumptions and false stereotypes will be cleared up.

Following are some basic tips to help you be more comfortable interacting with people with disabilities, and to help people with disabilities enjoy interacting with you more.

• Don't make assumptions. Don't assume you know what someone wants, what they feel, or what is best for them. If you have a question about what to do, how to do it, what language or terminology to use, or what assistance to offer, ask them. That person should be your first and best resource.

• Everyone is different. Remember that people with disabilities have different preferences. Just because one person with a disability prefers something one way doesn't mean that another person with the same disability also prefers it that way.

• Ask before helping. Before you help someone, ask if they would like help. Follow the person's cues, and ask if you are not sure what to do. Don't be offended if someone declines your offer of assistance.

• Address the person directly. Talk directly to the person, not to the interpreter, attendant, or friend. You don't need to ignore the others entirely; just make sure to focus your interaction on the one you are addressing. When a person who is deaf has an interpreter, they will look at the interpreter as you are talking. It might take a little extra effort to remember to face them rather than the interpreter.

• Be at eye level. If you will be speaking for some time with a person in a wheelchair, sit down so that you are at eye level with them so they don't have to strain their neck to look up at you.

• **Speak normally.** Some people have a tendency to talk louder and slower to people with disabilities; don't. Don't assume that because a person has one disability, that they also have a cognitive disability, or are hard of hearing. For example, a person with cerebral palsy might use a wheelchair, have uncontrolled upper body movements, have difficulty speaking, and yet have very good hearing, cognitive abilities, and intelligence.

• Use normal language. It's fine to use common phrases such as, "Do you see what I mean?" even to people who are blind. People who are blind often make comments such as, "I can't find what I'm looking for," and "I don't see it on this [web] page."

• Use "people-first" language. This means putting the person first, and the disability second. For example, say "a man who is blind" rather than "a blind man," and "a woman who uses a wheelchair" instead of "a wheelchair-bound woman." Use people-first language when speaking with people with disabilities, and when speaking and writing about people with disabilities.

• Avoid potentially offensive terms or euphemisms. Some terms many people find annoying or offensive are: restricted to a wheelchair, victim of, suffers from, retarded, deformed, crippled, and euphemisms such as physically challenged. If you are unsure, ask the person with a disability what terminology they prefer. Also note that accepted terminology is different in different parts of the world. To find out more about terminology in your area, contact a local disability association.

• Be aware of personal space. Some people who use a mobility aid, such as a wheelchair, walker, or cane, see these aids as part of their personal space. Don't touch, move, or lean on mobility aids. This is also important for safety.





# The **Importance** of **Self-Esteem**

By Bob Cunningham, adapted

People often use the phrase "selfesteem" when they talk about raising kids. But what exactly is it? And why does it matter so much for children with learning and attention issues?

Children's self-esteem is how much they value themselves, and how important they believe they are in their world. It's tied to how capable they feel. Positive self-esteem can make a big difference for children with learning and attention issues.

When children value themselves, they're more likely to stand up for themselves and ask for the help they believe they deserve. When they're confident and secure about who they are, they're better able to face and manage their learning challenges.

When children have high self-esteem they:

- Feel respected.
- Are resilient and feel proud, even when they make a mistake.
- Have a sense of control over activities and events in their life.
- Act independently.
- Take responsibility for their actions.
- Are comfortable and secure in forming relationships.
- Have the courage to believe in



their own values, and make good decisions, even in the face of peer pressure.

Children develop positive self-esteem by experiencing repeated successes. Past accomplishments show them that they have what it takes to face new challenges. Their success makes them feel good about themselves.

Their success also pleases other people, like their friends, and the adults who care about them. This also makes them feel good. Over time, success and the feedback that comes with it, help children develop the positive characteristics associated with high self-esteem.

Children with learning and attention issues often struggle to develop and maintain high self-esteem. It's not that they never experience success. It's more that their experiences are inconsistent.

Some schoolwork can seem impossible to do. Sometimes children with learning and attention issues are accepted by their peers. But other times, they're the target of cruel jokes.

As a result, kids with learning and attention issues can become increasingly uncertain of their own abilities. They might grow unsure of how to react to challenges.

Children with low self-esteem may not believe they're worthy of good treatment. Because they feel this way, they may not ask for help or stand up for themselves. In other words, they don't develop selfadvocacy skills.

Low self-esteem is also at the root of other serious challenges because:

- Repeated failure can lead to feelings of frustration, anger, anxiety, and sadness.
- Children in this situation often lose interest in learning.
- Friendships can suffer as frustrated kids seek negative attention.
- Children can become withdrawn or give in to peer pressure.

Building self-esteem is possible. Children can learn to improve how they see and value themselves. Being a supportive but realistic parent is key.

Praise your child's efforts, but don't lavish praise on everything he does. Children know when they've been successful and worked hard—and when they haven't. Asking teachers to also be supportive but realistic is important, too.

Helping children find friends who accept them for who they are can help them feel valued and supported.

Help your children discover their strengths and help them build upon them.

Activities that encourage cooperation rather than competition are especially helpful in fostering self-esteem.

Identify and redirect inaccurate beliefs

children have about themselves, whether they're about perfection, attractiveness, ability, or anything else. Helping kids set more accurate standards, and be more realistic in evaluating themselves, will help them have a healthy self-concept.

Give positive, accurate feedback. Comments like "You always work yourself up into such a frenzy!" will make kids feel like they have no control over their outbursts. A better statement is, "I can see you were very angry with your brother, but it was nice that you were able to talk about it instead of yelling or hitting." This acknowledges a child's feelings, rewards the choice made, and encourages the child to make the right choice again next time.

Be a positive role model. If you're excessively harsh on yourself, pessimistic, or unrealistic about your abilities and limitations, your kids might eventually mirror you. Nurture your own self-esteem and they'll have a great role model.

Together you can help your children bring out the best in themselves, and empower them to master the challenges that come their way.

"Building self-esteem is possible. Children can learn to improve how they see and value themselves."

# **Don't** Be **Afraid** to **Hire People** with **Disabilities**

#### Learning from one another has its benefits

By Rex Huppke, adapted excerpts



One of the best experiences of my life was watching Jamie Smith, a young man with autism, leave his routine in Chicago, travel to the Special Olympics World Games in the chaotic Chinese city of Shanghai—and succeed.

Jamie's success—managing in a foreign country and bringing home a silver medal—was the result of one thing: hard work. And I've yet to meet a harder worker than him, or a person who more appreciates the opportunities a job presents.

Our workplaces have grown diverse, but jobs remain far too scarce when it comes to people with autism or other intellectual disabilities. Unemployment rates vary depending on the study but hover around 80 percent, and people with disabilities who do get jobs are routinely paid less than other workers. A stigma surrounds people with disabilities, and employers fear that accommodating workers from this demographic might be cost-prohibitive.

Fortunately, some progress is being made.

The results, according to Deb Russell, have been statistically excellent. Turnover among employees with disabilities is 50 percent lower than that among nondisabled employees, and accuracy and productivity measurements are the same.

"People think adjustments will be expensive and daunting," Russell said. "What we found, especially on the accommodations front, is that it's minimal. Over the thousands of people with disabilities we employed, we've spent less than \$50 per person. A lot of the time, all the adjustment they need is an open mind."

What's important to realize is that when companies hire people with intellectual or other disabilities they don't do it as an act of charity. They do it because the people they're hiring are good employees.

And, dare I say, it's the way things should be. Our workplaces have always benefited from inclusion.

We should aspire to work alongside people with disabilities, not as an act of good will, but with the hope that we might benefit by learning from each other.



A bipolar disorder diagnosis can have a big effect on your job and career. In one survey of people with depression and bipolar disorder, 88% said their condition affected their ability to work. But a diagnosis of bipolar disorder doesn't necessarily mean that you can't keep your job. Plenty of people with bipolar disorder work and live normal lives.

You don't have to talk to your boss or coworkers about your bipolar disorder. Your health is your business. But if your condition has been affecting your performance at work, being open may be a good idea. Your boss and coworkers may have noticed the changes in your behavior. If you explain what's going on, they may be more sympathetic and helpful than you expect.

Some people with bipolar disorder find their current job just isn't a good fit. Maybe it's too stressful, or the schedule is too inflexible. Maybe it doesn't let them get enough sleep, or involves shift work that could worsen their condition. If you think your job is hurting your health, it's time to make some changes. Here are some things to consider:

• Decide what you really need from your job. Do you need to reduce your responsibilities? Do you need extra breaks during the day to reduce stress? Would you rather work independently or in a group? Do you need to work shorter

# **Bipolar Disorder** and **Your Job**

WebMD, Reprint, adapted excerpts

hours or take time off? Or do you need a different job altogether?

• Make decisions carefully. People with bipolar disorder are prone to acting impulsively. Think through the effects of quitting your job—both for yourself and possibly for your family. Talk over your feelings with your family, therapist, or health care provider.

• Go slowly. Returning to work after you've taken time off can be stressful. Think about starting in a part-time position, at least until you're confident that your bipolar disorder has stabilized. Some people find that volunteer work is a good way to get back into the swing of things.

Unfortunately, you may still run into people at work who treat you unfairly because of your bipolar disorder. Often, their behavior stems from ignorance. You might be able to head off problems by teaching people a little about bipolar disorder.

Some people with bipolar disorder feel they're treated unfairly at work; they might be passed over for promotions or raises, for instance. If you think you're being treated unfairly, there are things you can do. But don't do anything rash. Research the law, and talk your situation over with friends, family, your therapist, and your health care provider before taking action.

## My Best Friend Fela

#### She didn't give up

By Ke Rafitoson, adapted



For people in Madagascar who live with a disability, life is not easy.

Disabled people are often pointed at, isolated, separated from their families, or neglected. This is because disability is often considered a curse in a society where superstition is commonplace even if we prefer not to admit it.

My life changed, when I met Fela. Her life story opened my eyes.

#### **How I met Fela**

Back in 2006, when I was taking a course at the Friedrich Ebert Foundation called Youth Leadership Training Program, Fela Razafinjato was the only disabled person in our class of 25 students.

She impressed everyone with her frank, bold attitude, and her lack of psychological complexes about her disability.

It was then, at age 24, when we quickly became friends, and she told me about her lifelong struggles. A real success story compared to the lives of many other disabled people.

A disabled woman perhaps, but above all a fighter

When Fela was 3-years-old, she contracted polio and lost the use of her legs. Luckily, her parents gave her every opportunity to succeed in life.

Her mother insisted that she should receive the same education as other children her age, but most schools in Antananarivo—both private and public refused to let her attend. She was finally lucky enough to be admitted to a religious school, but at a considerable physical and psychological cost.

For years, she had to climb long flights of stairs on crutches, and her classmates laughed at her. But it would take a lot more than that to deter Fela from her goal of living a "normal" life.

Fela graduated from business school. She is now married and has two beautiful little girls. At the same time, she manages the Centre Sembana Mijoro (CSM)—an NGO that sponsors disabled children, and advocates for inclusive education.

Fela also opened an education center for children who have cerebral palsy, a condition that affects motor skills and requires constant care. The center offers two workshops—sewing and pastry making—which create jobs for women who have a disability.

As I said, Fela is a success story! In Madagascar, just being a woman is already a liability, but being a woman with special needs makes you feel as if you're carrying the weight of the world on your shoulders.

#### Together we mobilized change

Since 2006, Fela and I have collaborated through our respective organizations (CSM and the Nova Stella association, which I head).

Together we fought for the reform of Malagasy laws on persons with disabilities.

We prepared a practical guide on disability rights, to make the public aware that people with disabilities have the same rights as non-disabled people.

In 2009, we helped conduct a study on the inclusion of disabled children in Antananarivo schools. We found that disabled children represented only 0.26 percent of the total number of schoolchildren from 631 schools in Antananarivo.

Every day we try to come up with innovative solutions that will allow people with disabilities to live in a decent environment that is well adapted to their abilities. For example: find ways to accommodate public restrooms for people with disabilities, or building ramps outside public buildings.

Today, my friends and I are working on a volunteer basis. That surprises people, because Malagasies don't have a culture of altruism. We are often asked, "What are you getting out of this?" The simple answer is: the satisfaction of helping others and making a small contribution to a vital cause.

### Mobilizing young people and raising their awareness about disabilities

People living with and without disabilities should join hands, break down barriers created by the government,

and demand better living conditions for all.

There are already some enthusiastic young people that have teamed up to develop virtual platforms and discussions on social networks, showing that people with disabilities can also participate in these networks.

Other young people are following Fela's example and have chosen to act at the grassroots level, bringing people together to change their ways of thinking, and combat the wait-and-see attitude, and culture of begging that often prevail among the disabled community.

Where do you stand? What are you doing for disability rights? Even the smallest action is a step to bring about change. So what are you waiting for? Get moving! Whether it's for this cause or another, take matters into your own hands, and become an agent of change!



# Life with Disability



There is a plan and a purpose, a value to every life, no matter what its location, age, gender or disability.—Sharron Angle

The only disability in life is a bad attitude.—Scott Hamilton

The thing about living with any disability is that you adapt; you do what works for you.—**Stella Young** 

Disability is a matter of perception. If you can do just one thing well, you're needed by someone.—Martina Navratilova

My advice to other disabled people would be, concentrate on things your disability doesn't prevent you doing well, and don't regret the things it interferes with. Don't be disabled in spirit as well as physically.—Stephen Hawking When you hear the word "disabled," people immediately think about people who can't walk or talk or do everything that people take for granted. Now, I take nothing for granted. But I find the real disability is people who can't find joy in life and are bitter.—**Teri Garr** 

A hero is an ordinary individual who finds the strength to persevere and endure in spite of overwhelming obstacles.

#### —Christopher Reeves

I'm officially disabled, but I'm truly enabled because of my lack of limbs. My unique challenges have opened up unique opportunities to reach so many in need.—**Nick Vujicic** 

Your success and happiness lies in you. Resolve to keep happy, and your joy and you shall form an invincible host against difficulties.—Helen Keller

I can't change the direction of the wind, but I can adjust my sails to always reach my destination.—Jimmy Dean

Keep your face always toward the sunshine – and shadows will fall behind you.—Walt Whitman