EXTRA Xs and Os – We all need love

By Guest Columnist Mika Hartman

My husband and I have been married over 24 years. Celebrating us today is as important as it was our first Valentine's Day. The first one, CJ came to my work and left perfume on my windshield. "Tommy Girl" perfume became my new favorite; I can still smell it. Not because it was the most wonderful smell out there, but because it smelled of love - his love for me. No, I don't still wear "Tommy Girl," but I can't forget how this little box made me feel. We hadn't known each other very long… and 24 years later, I remember that day perfectly.

CJ and I have three children together. Our hopes and daily prayers consist of the exact same thing for all three children, even though they all have a decade between them: True love, passion for life, determination, and success at a level they feel successful (all up to each of them to decide what these are to them) - all with God as the priority. This list is the same for many parents, including mine.

For my two older children, these are achievable milestones, as they should be. They will be on a path of their choosing, and all doors are open them. They can dream big and do whatever their determination level goes for. It is up to them to achieve the life they desire. I don't have to advocate or change laws to see them reach their full potential or to walk through life with someone they love. Just prayers are needed.

My youngest child, Hudson, has roadblocks set up that many have no idea about. I didn't know all of them until his arrival. He's only 3, and, while the laws may be improving, there is still so much that dictates the life he can have. Hudson was born with Down syndrome, a large hole in his heart and transient leukemia.

It's "Love Day" month - did you know many people with disabilities are unable to be married because of the penalties that they would face?

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If two persons with Down syndrome fall in love and want to walk in this world together, they are penalized if they officially wed. The Federal Government says that they (the persons living with Down syndrome) will lose needed benefits if they marry, punishing them for seeking love at a deeper level. Supplemental Security Income (SSI) and Medicaid would deem incomes as joint, making the couple ineligible. And all cash gifts to the couple have to be reported as income, as well.

Other helpful programs, like Childhood Disability Benefits (CDB) and Social Security Disability Income (SSDI), would be affected because of the parent connection that automatically goes away upon marriage.

As it stands today for our friends: You can fall in love, but you can't get married. Or, you can get married, and face your challenges with no help. That's not American.

Love is a powerful gift, but it is not so powerful that your medical needs vanish.

When I asked for guidance on this issue, I was told by a good friend that he has a friend who is calling her wedding ceremony "fake" in order not to not lose their benefits. How awful to need to lessen or degrade the most important day in your life as "fake." Heartbreaking. But the person with Down syndrome recognizes that needed benefits trump a real ceremony.

It's also unknown that our friends with Down syndrome can be paid "subminimum" wage…. It's not even a real word, but it happens all over. This program was originally created to help open employment doors for people with disabilities. It was intended to help integrate the disability community and provide income that wouldn't disrupt any health services already provided.

But it worked against them, and it gave society the opportunity to devalue a person based on their disability. We are valued in life by our worth, productivity, opportunity and abilities. When a person is paid as little as 20 cents per hour, the message becomes that they are only worth that. Many states are making changes to this, but Mississippi hasn't yet.

Now, we don't pay 20 cents an hour that I am aware of, but how often do you see a person with a disability like Down syndrome working in your community? I live on the Coast, and I personally know of only one. You read that right! Many families find themselves in this very situation and either choose to keep their adult child at home or create an opportunity for the family to open a business.

Now let's put these two big dreams I have for my children together: Hayden and Henley can get married with a ceremony and a celebration of love; Hudson can't, not legally, at least, and still maintain the benefits he needs. My older children can do whatever job they seek and be valued and earn raises/have new opportunities; Hudson will be devalued by society and paid under minimum wage for doing his job, or I will have to create him real opportunity.

This is the first time I've typed this, and my heart is skipping beats.

Hudson's diagnosis is Down syndrome. He has a life expectancy of greater than 65 years old. He has a strong will, and he CAN do big things. Every other person in life gets to choose a path. Why can't Hudson? I also want to add this: God gave Hudson his extra chromosome. Hudson didn't ask for it. He was created this way. And he's wonderful. Different isn't bad; his different is beautiful. The world needs the love he gives.

Some will argue that raising the pay to minimum wage across the board for all will lead to unintended consequences; not all good intentions play out as all good. I have heard this one already several times on my path to bringing the needed change. If you force employers to pay more, then they may not hire at all a person with Down syndrome.

And that is the problem.

It is embedded in us that they (people with Down syndrome) don't deserve better and fair wages. If a person has the heart to hire based only on the bottom line, they missed the mark. This wasn't created to make a bottom line better. It was designed to integrate wonderful, loving, happy people into the workplace and provide opportunities for them to grow and learn as active and productive citizens in our communities.

Some will argue that marriage isn't important, either, or that it is not a reasonable request. I disagree. Having someone you love to walk through this world with and be your best friend on the deepest level possible is everything!

Now let's put these two together: Marriage and a great job that values your contributions… the dream for all of us, right?

Now the money part. Better wages and two incomes becoming possible for our friends may deem that all the extra assistance isn't needed. But I want to ask you to think about it this way: a person living with Down syndrome has many health challenges, ones you'll never face, and the cost of healthcare is very expensive.

Hudson was born with a large hole in his heart that will require multiple surgeries, transient leukemia, hypothyroidism, missing tear ducts, and more. All require medical attention. He also eats by a g-tube. His feeding equipment is over $2,000 per month. I've recently been denied a wheelchair for Hudson. The cost is thousands for his chair. Hearing that items on a wheelchair are "a luxury" is ridiculous. I need it for his safety on long walks, trips, and doctors' visits, because of his low muscle tone. His adaptive bike was $9,000. My point in sharing is that even with fair wages and two incomes through marriage, the necessary medical expenses that would no longer be covered by benefits if a couple marries can reach astronomical proportions, and a couple should not have to choose between medical care and love.

Love comes in many forms. It comes in a hand holding yours as you walk; it comes in a smile that cheers you up just when you need it; it comes in looking to the future with that special person.

Love can also be found in a mom moving mountains. I love Hudson so much, I will move these mountains; I have to. My dreams for my children will remain, though my prayers are different for Hudson. I pray I can be the voice he needs. I pray that he won't know all the discrimination that is out there when I am done. I pray he gets the life he deserves. I pray that life gives him the love in return that he gives. With God, all things are possible. Any help moving these mountains is truly appreciated.

February is Congenital Heart Defect (CHD) Awareness Month. Hudson is a CHD Warrior! Celebrate all our little fighters with me; they are heroes!

To help, please contact your local Down Syndrome organizations to find out how to get involved. If you'd like, you can follow Hudson's journey on Instagram at TeamHudsonTheStrong.

Extra hugs and extra kisses this February. Remember that love conquers all.

EDITOR'S NOTE: CJ and Mika Hartman are personal friends of Pelahatchie News' *publisher, Clay Mansell. We wanted to use our publication to share Mika's journey as she works to change laws, perceptions and anything else she chooses to tackle to make our state a better, more inclusive one. Her son, Hudson, has Down Syndrome, and she will share his journey and hers as she works with lawmakers to make Mississippi a better place to live for everyone. Please visit our website to view her blog and important information on how we can all help make Mississippi better.*