



Dear NT caregiver of Autistic child,

There is so much between us to be reconciled.
I am autistic. My family are NTs
I'm 30 years old with a PhD
In behavioral science and I work full time
To express myself, I often use rhyme.
I'm artistic, athletic, a sensory seeker-
I played soccer through college and I'm also a keeper.
(That's a Harry Potter joke if you didn't quite catch it,
And too good of a pun for a keeper to pass it).
I live on my own for most of the year,
But for several months, too, my mother lives here.
I need constant movement, I need a routine.
I comprehend best that which I've seen,
And not what is heard, I don't look in your eyes,
when I'm working so hard just to summarize
In my mind, that which you say
So I can plan out my thoughts and then I just may
Be able to respond and hold conversation,
a demanding task, that I use in moderation.
And follow with down-time in pure isolation,
a very real need, regardless of social motivation.
I still get overloaded with social and sensory
I still go non-verbal in times of intensity.
I do feel empathy, it's overwhelming and strong,
and it freezes me up: and my reactions seem wrong.
I smile when happy, I smile when sad,
I smile when terrified, I smile when mad.
I can be literal, and I love a good pun.
And playing with words and numbers are fun.
I feel the stars, and nature's symmetry,

I seek comfort in patterns and geometry,
Small talk is baffling - it's meaningless sound,
Silence is beautiful when it surrounds,
And I can be lost in the depths of my mind
in the peaceful retreat that i control and design.
I can drive, I can shop, so long as I plan,
I can get through my work day as long as I ran,
Or lifted weights and my schedule is known,
And for all tasks where possible I can be on my own.
I minimize face time, and I take lots of breaks
And i remain vigilant of the energy it takes
To complete each task and to get through each day,
And I counter those risk factors with movement and play.

Yes - I am different from your daughter or son,
But i'm certain there's overlap; and more when I was young.
My mother could leave me for hours on end,
and I'd entertain myself unaware of times when
People came in; it couldn't break my attention
Sometimes not attending to my name that was mentioned.
I could do well in games and tasks that had rules,
in predictable settings and I did well in school.
At least in most subjects but others weren't passed,
Those I deemed useless, non-functional tasks.
I couldn't wear socks! The seams were pure hell,
i would scream and fight and kick and yell.
I couldn't stand the sound of people chewing or breathing,
It wasn't just annoying, I wasn't just seething.
It made me explosive; I'd throw tables and chairs,
I'd lash out at my brother and I'd cover my ears,
And cry and melt down and sometimes get violent,

or run to my room seeking the silent,
And stay there for hours where the chaos was gone,
And the world was so safe when I was withdrawn.
Some nights I would stare out my window 'til dawn,
and it was magic and wonder - it never felt long.
But most nights I would sleep so deeply and sound

that when I woke in the morning my mom or I found
That I had wet the bed; this went on through senior year -
my mother tried everything but now it's so clear
that it wasn't about liquids or timing or hydration;
It wasn't immaturity or lack of motivation -
I never even sensed it; below my threshold for perception
A hyposensitivity in interoception.

I'm not here to tell you you're evil or cruel.
I'm not here to shame you or call you a fool.
I'm here to join forces and to work as a team
to learn from each other; to plot and to scheme:
How to improve this world for our youth,
And how to best advocate for science and truth
As it applies to autism support and accommodation
And resources and training and goals for education.
Too often it seems that efforts are wasted
on misunderstandings from two different bases
With caregivers unconvinced that we're actually autistic
And autistics insistent that caregivers don't listen.
And both sides unyielding and both sides decide
That the other won't change for as long as we've tried.
No progress is made, no knowledge is gained,
nothing comes of it but a bitter exchange.
And change is hindered and progress stands still,
Like a microcosm of the issues on capital hill.
Divided and extreme; no attempt to compromise.
Nuggets of truth strategically weaved throughout lies,
And everyone more comfortable with what they think they know,
than seeking out feedback to learn and to grow.
I would never deny the critical insight
Of autistic adults in learning what is right
And listening to those who have lived through the process
cannot be written off as uninformed nonsense.
Or attention-seeking, or too well-spoken to get it,
Or misdiagnosed. And self-diagnosed? Then forget it.
NO - that is wrong and it's ignorant too
And so often it happens and nothing gets through

So please NT parent, before you dismiss,
Hear us out and listen to this.
We can mask, we can fake it and hold it all in
We can learn to look “normal” and learn to “fit in.”
We can make you feel better by suppressing our needs
We can work for rewards and do as you please.
We can talk more and chit-chat, and we can flap less
We can not let it show when we experience stress.
You can control us, and we can comply,
You can feel happy, because we’ve learned to lie.
I recognize fully that I can’t understand,
Your social drive; why it’s so bad to stand
Out from a crowd; be unique; an outlier,
I just don’t experience that same desire.
To be like everyone and go with the flow,
society would be stagnant, we never would grow.
Diversity is natural and a need for survival,
yet we work so hard to tame and unravel,
That which is different, and that not like you,
As if humans prefer comfort over that which is true.

So if you like normal, then normalize stimming,
normalize flapping and normalize spinning.

Normalize stacking and focus and seeking. Normalize communication other
than speaking.

And logic and reason and literal minds
And intense special interests and details so fine.
Be mad at “professionals” for being sorry to say
That your child has autism but it might be okay
They might just be normal! There may be a way
Maybe just maybe you’ll have a real child someday.
Be mad at the doctors and their bold audacity
To tell you all the ways that your child will be.
MDs aren’t experts. It’s not their specialty
They’ve read one chapter in med school... ONE CHAPTER! maybe!
Be mad at the system for being stuck in the past
Be mad at society for refusing to ask

Or ignoring the experience that autistics do share
You've been misled... and that just isn't fair.
And it's also not fair for us to ignore you.
I want to know more! Really! We all do!
I want discussion and sharing of ideas
And more productivity and a lot fewer tears.
I hate this division; i want to do better
I want us to thrive by working together.
I hope you'll write back and tell me your tale,
Because we'd be a force i believe could prevail.
So happy world autism day! Let's celebrate,
then let's join forces as it's never too late.
Sincerely yours, With all my best,
Autistic Adult with NT parents.

- Jacquelyn Fede, PhD

Originally posted on 4/2/2019
www.itcannotbecontained.com



Jacquelyn with Momma Fede, an amazing parent “who just got it.”