

Dear Chaya and other Unicorn Moms,

I preface my words with an apology:

I don't know you; I have no clue what you're dealing with or what your child's needs are.

From your letter it seems like you're dealing with an immense challenge. I've taken time to absorb the emotions behind your words and the message you're delivering.

Forgive me for even having an opinion or daring to open my mouth.

But I've heard similar thoughts to yours, from the moment my daughter was born.... and I want to share my response to that with you and the broader Yahalom community.

You call me a Down's mom.

You think I'm one of hundreds.... that I've got built in support system, that's it's all been figured out and I'm walking a known, well-worn path...

Because my daughter shares a diagnosis with so many others.

Here's what I've been wanting to tell you for so long:

True, my daughter has DS. Her diagnoses didn't take much, one standard test and we knew her exact chromosomal count.

And....?

And that's it.

That's all we knew.

Her diagnoses did not tell us how she'd grow up, how she'd function, how many medical issues would pop up, the gagging, the choking, the weight fluctuations, how many skills she'd gain only to lose them to apraxia, seizures, medical traumas, extended hospital stays, and early onset dementia.

Just like you, I go to events and retreats and the comparison wheels starts whirling.

She shouldn't be here, they have it better, they have it worse, well at least HER daughter gets to be mainstreamed, at least THEIR son can express his needs in clear language. They belong here, I don't. I belong here, they don't.

I struggle with those comparisons.

I feel jealous of the children whose challenges are physical and not cognitive.

I feel jealous of the children who don't wear their diagnoses on their face, and at least get a chance.

I compare and judge and I think I know what others are dealing with.

After my first mixed special needs event, I was in a bad place.

I was overwhelmed by those dealing with so much more than me and gripped by jealousy over those who (seemingly) had it so much easier (why were they even invited?!!!)

I felt that events should be separated by diagnoses, especially for Down syndrome.

And then I went out in the DS community and I realized they'd need to separate us by:

- verbal/nonverbal,
- mainstream, partially mainstreamed, completely special ed...
- medically involved, overall healthy
- vision impaired/hearing impaired/cardiac impaired/seizure disordered
- sensory issues
- independence level, emotional and behavioral challenges
- etc etc

...and should any organizer attempt that selection process, I'd end up by an Event-of-1.

Just myself, with my one-of-a-kind child.

Yes, I've found support in the Down's community,

I've also found deep conflicts (nothing personal) differing opinions and vociferous arguments. (Imagine a vaccine debate... yeah, something like that).

There are "Down's mothers" (how I hate the term!!) who I can barely have a conversation with – so much are we on 2 different planets.

I've made deep friendships with mothers of otherwise-challenged kids: sometimes we are much more in line with our attitudes and approaches than with same-diagnoses club members.

Our children are not "Downs". They are individuals with varying degrees of challenges. But often they are not seen that way... not seen for their strengths... and not seen for their challenges. Just lumped into "Cutie Down-town", into "Downs" classes and "Downs" schools.

Special needs schools and camps have been known to get inquiries: "Do you accept "Downs"? If yes, I cannot send to your program. Make sure she's not with "Down's".

I've had it said to my face: My special child is almost-normal, I don't want her to be with "Downs". (a horrible term in my opinion)

No word about skill level, just diagnoses.

Yes, we (kind of) stick together. But if we're rejected from the special needs world and we are also rejected from the "mainstream" world, where does that leave us? If so many doors are shut in her beautiful slanty-eyed face... does she even stand a chance?

There's plenty pain in DS.

To you unicorn moms I ask: Have you met us? Are you interested in the “real” journey? Or is the only thing you see “Cutie Downs”? The ones who have it so much better, so much easier...

What I’m trying to say is this:

I too, am a unicorn mom.

I too am navigating the unknown.

I too feel alone in my journey.

I too face daily questions with no easy answers – or no answers at all.

I too have been warmed and encouraged by “real” people saying it the way it is.

I too grieve the child I wanted – but will never have.

I too am pained to the core when others so easily accomplish what my child cannot do.

I too spend my days and nights searching for answers and methods, trying testing tweaking and crying when it fails to deliver.

I too have felt patronized by pat-statements “you’re so special” “she’s so adorable” “we love Down syndrome” etc. etc.

You look at my journey as an easy well-worn path, tried and true.

It is anything but.

While I am very blessed to have a diagnosis that comes with so much research and knowledge, I am still navigating the unknown – my daughters’ unique profile, her unique life.

I too am figuring out (or floundering in) my next steps, getting to know my daughter one day at a time...

Forgive me if I sound insensitive to your challenge.

Letters like yours Chaya, remind us to be grateful for what we have.

There’s still pain....

Yes, we are very lucky that DS usually comes in a cute package –

....for the first 10-12 years of life.

And then comes the rest....

I’m real enough to know that “adorable” will fade. We hope and daven and work endlessly on her skills so that dignity, maturity and independence will grow in the place of “cute”.

But there are no guarantees....

And even if she will grow into a mature and lovable young lady in our eyes, will the world be able to see that? I worry for her future.... About who will be there for her, how easy it is to take advantage of her... what happens in our old age? How will she navigate a world that doesn't see an individual – they only see a group, a kind, a diagnoses?

And so I ask of you, are there really any horse moms, unicorn moms or zebra moms?

Can we stop grouping, labeling and stereotyping?

Because all I am is a trying-my-best mom to my one-of-a-kind little girl.