

Does it Matter?

How does our family deal with the diagnosis of ‘undiagnosed’?

Our daughter is nearly 3, she is healthy, happy, cheeky, naughty and everything that typical 3 years old are, except she:

- Can't walk
- Doesn't speak
- Is unable to feed herself

All of this to date has meant she has Global Developmental Delays in ALL areas. After many assessments we can ascertain that she is roughly at the developmental stage of a 12 month old - in SOME areas, a 9 month old in others.

For the first 6 months after finding all this out we went through a minefield of emotions and doctors appts trying to find out how we can help her start ‘reaching’ those milestones that all of our children are held up to. We kept asking for answers as to ‘what condition she possibly has’ in the hope it would give us the answer to HOW we could help her. Again, more confusion and angst when doctors kept giving us blank looks and very little advice. And are we the only family with this diagnosis because we can't find a support group for us?

We blitzed the therapy in the first 12 months, went to the various specialists and in the end I have to come back to the very first comment given to me by our Doctor:

“Take her home, love her, give her everything else you give your other children and she will do things in her own time”

It is only now that those words ring home to us. Therapy is essential for early intervention but it does not rule our lives. In fact we have cut right back from racing around every week to monthly visits. Her best therapy comes in the form of our home, her sisters, and her day-care friends.

We have come to a wonderful conclusion that I wanted to share with other mums that might be in the same situation.

“ It really doesn't matter”

Sometimes they can be empty words but the truth of it is ... it really DOESN'T matter. These children with delays should NOT be measured on the same percentile chart as typically growing children. (A very prominent doctor in Europe has personally told me this) it's as simple as that. As parents it's blatantly obvious to us that our children ARE NOT like others of the same age. Why must the medical profession keep reminding us that they are way under the ‘norm’?

Yes we have essentially had an infant for 3 years, which has meant some extra work, but our life is by no means hard. It's important to remind myself of that every day. I have a nice home, a loving family, my children are in school, we have food on the table every night (well almost). Yes we have a member of the family with a ‘disability’ but honestly – the 5 year old is harder (is there a support group for that??)

So to other mums who perhaps feel that having a diagnosis of GDD is frustrating you and providing dead ends, I would offer the advice that we should take that diagnosis as a blank canvas. Our children have no limiting criteria on them – they can achieve anything and will no doubt surprise all of those who said they would never walk, talk, eat or sit unaided.

If you have a story you think can help others, please email it (with or without a photo) to info@theumbrellanetwork.org