After an autism diagnosis, the world shrinks. It doesn’t happen right away. It’s subtle. Sneaky. After your child’s diagnosis, you are thrown into a sea of information – an overwhelming tidal wave of theories, therapies, treatments, studies, statistics. You grab onto what you can, hoping that information will keep you afloat, swimming, swimming, fighting, fighting. You keep on struggling, alongside your spouse if you are lucky enough to have one, and with your children who fight in a different way but just as hard. You never notice the movement of the tide, nor do you mark the day when your feet make their way onto land. Time goes by, and finally the day comes when you look around in puzzlement at the deep waters that surround you, and at the island you find your family standing on. “Where are we?” you might ask. “How did this happen?”

Nobody ever tells you that when you have a child with autism, you lose your friends. It sounds harsh. But it’s true. It starts when you turn down invitations to dinner because your child can’t handle the sensory overload of a restaurant. You skip celebrations and parties at friends’ houses because your child doesn’t like unfamiliar environments, and may harm himself if the place isn’t completely child-proofed. Going anywhere new is traumatic for your child and for your family, so it’s simpler to stay at home. After a while, the invitations dwindle. There are only so many times you can turn down an invitation before the person gives up on you. That’s when it happens. That’s when the world shrinks. Your friends become distant, not because they haven’t tried, but because you have set yourself apart on your own little island. You didn’t do it on purpose; you were simply doing what you thought was best for everyone. You were keeping your child safe and content; you were protecting your family from embarrassing situations, from public scrutiny. Unwittingly, you have planted yourself and your family on an island – a lonely one – and it seems too late for rescue.

I’m here today to offer you a lifeline. You are NOT stuck on that island! Your world can expand again. For seven years, my family and I lived on that island, and it was a lonely place to be. Only now are we starting to build bridges back to the mainland, to go places with our child,
to accept invitations, to really *live* again. We’ve found that the world is a more welcoming place than we imagined. Once people understand our situation, they are more than willing to accommodate our needs and to accept us as we are. Autism does not come with the stigma it once had, and people are eager to learn and help.

I know that there are many families like ours “out there.” Each on its own little plot of land surrounded by uncertainly, fear, and grief. It doesn’t have to be this way. We need to find each other, support one another, and find our way, together, back into the big, beautiful world.

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