

Published on *VirginiaNavigator* (<https://virginiannavigator.org>)

Isolation for Special Needs Families

“Who is going to take Ava to her soccer games this week?” my husband asked, concerned.

“I don’t know. I will think of someone to call,” I responded, although I cringed at the thought.

Did I have anyone to call? When was the last time I had spoken to one of the moms who had kids in Ava’s class? I wracked my brain and remembered one playdate over the summer she had had. I called that parent, but she was unable to help. She was sweet and gave me a list of other moms that were carpooling. She didn’t understand; carpooling was part of the island life, and we had moved away from the island years ago.

School used to be such a place of isolation for us. I dreaded going into the public school more than anything, and yet I will bet that I was called in more than any other parent there. I can remember one time being called into a meeting with Jony’s second grade teacher. She was a safe place for me and for him. She had kind, warm eyes and a generous smile, and although she couldn’t reign in my son’s behaviors, she always landed in a place of compassion for him.

I put on my cloak of defense that morning – the cloak that demanded the IEP be followed and his needs be considered, the cloak that protected me from my own tears and vulnerability. She greeted me with a warm hug, and I felt the cloak slipping off my shoulders. I don’t remember what the meeting was about – there were so many meetings! About 10 minutes into the meeting, the P.E. teacher barged into the room. He said, “I am sorry to interrupt your meeting, but I heard you were here, and I need to talk to you about Jony.” He didn’t look sorry; he looked angry. His speech was pressured and irritated. I don’t remember what he said, but I remember how I felt....smaller and smaller, wishing the ground could swallow me up. Before he was done, the school counselor came in to pile on the complaints, full of criticism,

judgment, and annoyance. I remember standing up, willing myself to advocate, but I couldn't find any words, so instead I babbled, "I need to go - maybe you can just email me." I rushed out the door, hoping I could get to my car before bursting into tears, and the music teacher rushed out of her room as I hurried by. "Do you have a minute? I really need to talk to you about Jony," she said. "No, I don't," I replied as I hurried past her surprised gasp. I made it to the car before bursting into tears.

Experiencing Isolation

Experiences like this pushed us into isolation. We only participated in the mandatory holiday parties. I became an expert in avoiding eye contact and conversation at school activities. Too much friendliness always seemed to lead to a conversation, and that always led to complaints about Jony. I used to pursue social contact, but as the years got more difficult, I began to avoid it. It was just so much simpler not to interact too much with people.

We started out on an island with everyone else, but we were sometimes pushed, sometimes moved away willingly, until the only place to go was out to sea. We built a raft; at first it was rickety, and the water threatened to overwhelm us, but eventually we added to it, making it sturdy and safe. We created our own world away from the island where we created our own entertainment, safety, peace, and sometimes rest. There are other families on rafts. We see them and bump into each other once in a while. Sometimes our rafts are tied together for a bit and we visit, but each raft is built for the specific needs of the family, and often these needs conflict. On one raft a child can only calm down by using his iPad, but on our raft, iPads are prohibited. Mostly we relate from a distance: phone calls, emails, texts, and thoughtful gifts.

Then there are the island people. We still have island friends. They are kind, warm, and flexible, and they work at staying connected. It is hard to stay connected to a raft family. When we finally get to the island activity, we spend the majority of our time meeting needs and little time engaging in the social activity.

Then there are the children on the raft who are only there because of the needs of other children in the family. These children long to be part of the island life. They live in constant dissonance, wanting both to be on the raft and to be on the island. They go to all the island get-togethers, but they usually can't host any. There just isn't any room on the raft for extra people. Even if there is room on the raft, they

understand that islander children don't understand raft life. Islander children wonder at the high structure of the raft, paired with what seem to be low expectations. There is great sadness for these children. They understand all they miss, and as a result develop a greater sense of maturity. The parents on the raft understand that island children can survive on a raft, but raft children cannot survive on the island. It is a price they know is unfairly paid by the child who would thrive on the island.

Making Connections

We still live on the raft, but we visit the island frequently now. At some point along the way, we got used to the sweetness of the raft – the way it doesn't matter what you have there or who you are – the way you focus on all the treasures you have, and they seem so many while you are on the raft – the closeness of the people on the raft and those sweet friends that join us here on occasion. In changing schools, we have met a community of raft families, families that do all the things island families do but with different expectations and much different conversations. All of us, regardless of jobs, social standing, or finances, have chosen to leave the island because the water is kinder to our children. We started to feel less isolated and more connected.

There are some families that are able to move onto the raft for a season, coming back to the island restored. Other families stay on the raft forever. Every family's goal is not to move back to the island, because some children will never thrive there. For these families, the goal is to find the sweetness of the raft. The goal is to connect with the people on the raft, and to stay connected with people who matter to you.

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Last Reviewed

Saturday, March 2, 2024