

Autism Journey continued (Day 2)

Written by Gayle Nobel

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I'm going to share more about my experience with my brother Philip.

After he moved here, he lived in a couple of different institutional settings. I don't know what the process was for my dad to find these places because I was not involved. I remember visits with him in my early teens. They were often awkward and uncomfortable and the institutions where he lived were not too nice. In fact, he was abused and we have the gruesome photographs to prove it. At some point, my mom and I stopped going but I don't think my dad ever did.

During one of Philip's hospitalizations, a volunteer made a connection with Philip and continued to see him for many many years after that. Philip was beginning to have a life outside of the institution. He went hiking and traveled and spent time in his new buddy's home over a long period of time. My dad even made him co-guardian.

When they closed down the institutions here in Phoenix in the year ?, Philip moved into a group home run by the state where he still lives today. This was quite a step up from the previous living arrangements. At least it was a home environment. I didn't see him for many years. By that time, I was starting my own recently married life and having my own children. For a long period of time, I confess to not wanting to visit him because I was afraid to see Kyle's future. I was scared of what the adult years would bring for Kyle.

When I took over guardianship in 1995 and attended the first ISP meeting, I met Philip for the first time in both of our adult lives. And it was ok. There was nothing to be afraid of after all. It was shocking to see he was a grown man but when he looked at me with those big blue eyes, all I could see was his sweet sweet soul. He was my brother, yet he was a stranger. It was hard for me to feel connected to him because we grew up apart. It's been a process for me to find a way to connect and he's the one with the autism :-).

We have a long way to go in supporting adults with autism on all parts of the spectrum. But we have come so very far. I worry about Kyle's situation after we are gone but I also trust we will somehow figure out how to create something good.

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