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DES Celebrates National Down Syndrome Awareness Month

Client shares story of appreciation for DES services

PHOENIX – Gina Johnson moved to Phoenix with her family in the mid-1980s. In 1985, Gina gave birth to a son named David. David was born prematurely and diagnosed with Down syndrome, a genetic abnormality where a baby is born with 47 chromosomes instead of 46. The extra chromosome causes abnormalities in the development of the brain and body. “I did not know anything about Down syndrome,” said Gina. “I remember thinking at one point that it was my fault, maybe I had done something during the pregnancy that caused my son to be born with this disability.”

Gina also remembers that in the early years she had little to no contact with social workers. “Once I was home, I would receive periodic phone calls from social workers at the Department of Economic Security (DES), asking how we were and if we needed anything. I would always politely deny their request for help. I had a loving husband, who had a great job, and I was able to take care of my family. I didn’t need social workers coming into my home.”

All of that changed when David was six years old. One day, Gina received her periodic phone call from DES. During the conversation the social worker made a comment that caused Gina to stop, think, and focus. She invited the worker over for a visit that would not only change her life, but the lives of thousands of Arizonans since.

After meeting with the worker, Gina realized there were so many types of services available to her and her family that she had never considered. “DES gave services to not only David, but to my whole family,” she said. “They provided us with respite care, habilitation services, and something I never thought I would have: peace of mind and a quiet moment.” Gina remembers sitting on her couch one day shortly after the community provider took David down to the park to play. “I was sitting on the couch and suddenly realized that I could relax. I was so used to always keeping track of David to ensure his safety. I realized I trusted my child with the DES provider and that they cared me and my family, that we were not just another case.”

Gina continued using DES services as David grew through childhood into adulthood. David is now almost 32 and Gina is still thankful for DES and the services provided not only to her, but to other families like hers. “It is not just the workers in the Division of Developmental Disabilities who are angels. It is also the DES employees who help families receive food stamps, cash assistance, unemployment benefits, child

support services and so much more. Arizona is blessed to have the thousands of dedicated DES workers, statewide, willing and ready to serve.”

As the years went by, Gina realized other parents out there were still in need. In 1985, Gina started hosting monthly meetings with other families with Down syndrome children in her home. Gina now runs *Sharing Down Syndrome Arizona*, a non-profit organization which provides resources to families in Arizona. Every time a new family is referred to her organization, Gina personally goes out and meets the family. She provides them a small resource kit, and more importantly, someone to talk to. “When we started I had five families who I worked with. Now, I have over 4,000 families all across Arizona who are part of my family.”

To learn more about Gina and *Sharing Down Syndrome Arizona*, please visit: <https://www.sharingds.org/>

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