



**The Arc**  
New Mexico

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**The mission of The Arc of New Mexico is to improve the quality of life for individuals with developmental disabilities of all ages by advocating for equal opportunities and choices in where and how they learn, live, work, play and socialize. The Arc of New Mexico will promote self-determination, healthy families, effective community support systems and partnerships.**

## **End the DD Waiver Waiting List Campaign Edition**

### **No More Waiting – Jesse Farmington, New Mexico San Juan County**

Jesse is 11 years old lives in Farmington. Jesse was born with Pelazeus Mersbacher Syndrome. Pelazeus Mersbacher Syndrome is a rare genetic condition. Jesse needs full time care. He uses a power chair, has to be fed and bathed and supervised all the time.

Jesse is fun, loving, outgoing eleven year old. He loves participating in Special Olympics, sports and hanging out with his friends. Jesse attends Mesa Middle School in Farmington.



Jesse's parents want Jesse to be full functioning whether he is at home or in the community. They want him to be able to have what he needs as far as equipment, technologies, etc. to help him communicate as he grows.

When he was one year old he was placed on the Developmental Disabilities Waiver waiting list. He was recently funded after 10 years waiting. Before being funded by the DD waiver, parents depended on work insurance for everything needed. The copays were very high for Jesse's needs. The DD Waiver will help provide what he needs to allow him to succeed physically, mentally and verbally in every aspect of life.

Mr. and Ms. Armenta would like to say that they are raising their son Jesse to be a responsible loving, caring, outgoing individual. In order for Jesse's parents to do this they need what the DD Waiver will help with. It costs quite a bit to keep him progressing as a young child needs to be. The DD Waiver is a program that provides families and individuals with disabilities everything needed for physical, mental and verbal progression. It helps parents to know that they can

provide what will come up, without having to worry where or how they are going to get equipment, therapies, or other medical care for their son Jesse.

**I am Waiting - Clifford**  
**Aztec, New Mexico**  
**San Juan County**

Clifford is a 16 year old young man who has Cohen Syndrome. Clifford's condition causes visual and mobility impairment, Cohen Syndrome is a rare genetic condition not recognized by the State of New Mexico guidelines through Department of Health, Developmental Disabilities Supports Division, but does meet federal guidelines. Consequently, when Ms. Caldwell, Clifford's mom applied for the Developmental Disabilities Waiver in 2009 Clifford was denied in 2012. Clifford is going without needed medical services.

Ms. Caldwell is not doing well and needs help to provide necessary medical care, therapies and services. At this time Clifford is 16yrs old and attending Aztec High School. Clifford is a junior this year and is currently participating in band. He is also in the work skills program. Clifford is currently with the San Juan Special Olympics team in Bloomfield and loves to participate in their activities.

Ms. Caldwell would like to see Clifford live as independently as possible. Clifford's impendence will be severely limited if assistance through the DD Waiver is not provided. The stress on parents is high and their health is affected. The DD Waiver will give needed medical care and provide adaptive equipment and supports. If someone meets federal guidelines, then the state should not deny services.

**I am Waiting - Aiden Castrillo**  
**Silver City, New Mexico**  
**Grant County**

When our son Aiden was born, it was the happiest day of our lives. He was such a blessing to us and our family and has been since then. When we found out he was born with Down syndrome, something we weren't prepared for and didn't know much about, anxiety set in and we were immediately concerned about the obstacles he would face. We love him so much and just like any other parent, we want the best for our son and we don't feel like he is getting the attention he deserves and is entitled to.



Aiden is currently receiving services thru Early Intervention; unfortunately, due to living in a rural area, he is not getting all the services he is eligible for. We have been patiently waiting and every day that he does not have the resources he needs is another day that he is behind on his development. Time is of the essence.

When we called DDS division inquiring about the waiver, we were told Aiden was on a "Child Pen State" and he was too young to qualify. They will not test him until he's 6 years old and make a decision at that point. However, if it isn't his turn for money he will have to wait. If Aiden was allocated a DD waiver, we would not have to pay any co-pays for his speech therapy. We are more than positive that with the right therapists and resources, Aiden will thrive. We see the improvement every day, can you imagine what he can achieve if he could qualify now?

When he was born he was flown to Albuquerque where he was in the NICU for a week, we are still recouping from the expenses incurred. The DD waiver will relieve so many worries both financially and emotionally. This is an investment, at a time when these children are absorbing all they can, the rate of return is more than you can ever quantify.

**I am Waiting - Caitlin**  
**Santa Fe, New Mexico**  
**Santa Fe County**

Caitlin is 10 years old. She is mostly nonverbal. She can request certain things, like when she is hungry or thirsty, or needs to use the restroom. She has MANY sensory issues, both physically and orally.



My daughter requires ABA therapy services that are not currently being obtained right now. This service runs about \$75.00 per hour. This service teaches my daughter how to cope with changes in schedule; how tasks must be completed before a desirable task can be obtained. My daughter also requires additional speech, physical therapy, and occupational therapy services. My family is only able to afford one additional hour a week. My daughter requires orthotic prosthetics. We have not been able to afford updated inserts due to her foot and shoe size growth. My daughter has feeding issues and could use feeding/nutrition therapy services. My daughter requires assistive technology such as an ipad, and a trained individual to assist her in the use of it for communication and schedule training.

We have been on the waiting list since 2006. When we got diagnosis of Autism, we applied through HSD to get on the waiting list. Our application was lost. We applied again in 2006. Our application was again lost. In 2006, the Governor created a children's cabinet, and they conducted town hall meetings. I attended one of those meetings, and when I spoke about paperwork being "lost", I was asked to give my information to staff on hand. My original paperwork was found, and mailed back to me in an unmarked envelope. It is now on file as of 2006. My next issue deals with DOH not having my daughters IQ testing on file. I have submitted that paperwork twice. The Taos office closing has really affected our application.

We are NOT able to afford the services that would aide in getting my child self-sufficient. My daughter randomly has meltdowns and cannot find words to let us know what the matter is. We cannot tell when she feels sick, unless she actually vomits. Coping is very stressful for our family. We are constantly looking for discount or free services. We have cut back on our own household budget to be able to afford educational materials for home to help her move along with curriculum in school. We can't afford any family getaways, and end up in back yard camp outs. This is a result of no ABA therapy services. We could benefit from parent training on what/how to work with her. A lot of times we spend more time being teachers rather than enjoying parenting, and enjoying down time.

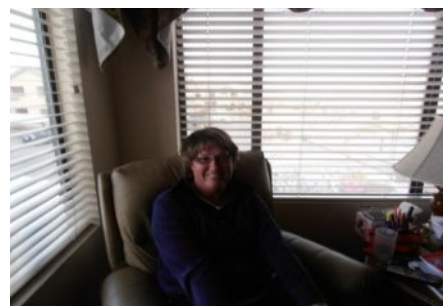
My dreams and goals are to get my daughter to become a successful and independent individual. My dreams are independent living and a career she can be proud of. My dreams are that she can communicate her wants, needs, and desires more easily, without frustration. My dream is that she remains safe and not be at danger because of her over friendly nature. My dreams are that she will blossom in the person she is meant to be.

I do not feel confident that the DD Waiver will come to us within a time that is meaningful to her learning abilities. She is in need of many of these services NOW. Another five or six years is not as helpful as right now. When I applied, I was told five year waiting list. I lost one year through application errors on HSD part. Currently we are at seven years, and nowhere near the top of the list. If we were to get off the list, I would be able to proactively get her into the therapy services she needs (ABA), and intensive speech therapy. Once she is starting to show improvements, I would be able to phase down on those and add in other therapy services. I would be able to get her the orthotics that she needs, to provide her more physical supports.

Sir/Ma'am, my daughter has been on the DD Waiver for seven years. The longer my daughter does without the services that I cannot afford, the more likely she will have to rely on social programs as an adult. Getting these individuals the help and supports they need at an early age, and support from family members will help these individuals to become successful and independent. I ask that legislative bills be approved and signed into law to help families like mine begin to help our loved ones on this long journey we have ahead of us. Funds for the DD Waiver will free up dollars in the future for most of the individuals who get the services needed. Thank you for your support in this legislation.

**No More Waiting - Corie  
Las Cruces, New Mexico  
Dona Ana County**

My name is Corie and I would like to tell you my story. I am 41 years old, and I live independently in Las Cruces New Mexico. I work at Camino Real Middle School as a lunch monitor. I was diagnosed with Cerebral Palsy at birth.



In October 2012, my name was finally taken off the DD waiver waiting list. My name had been there for 9 years. Being on that wait list was a difficult time for me. Even though I was receiving some help from Tresco there were still some support services I lacked. I had to depend on my parents for help to get me services that could make my independent living somewhat easier. It took a lot of phone calls, letter writing and a long paper trail by my father to get the help and supports in place, I have a job coach who drives me to work, I have a support system in my home a couple hours a day during the week to help me prepare meals, work on a budget, drive me to choir, and be a social companion. During the weekend I spend the time with my mother and father.

During the nine year wait list my father would call the Department of Health to see about the wait list, when my name was placed there he was told services would take as long as three years to begin, after those three years passed he was told the wait would now be five years. At one point my name was almost taken off the list and my father had to write letters and make phone calls to make sure I did not lose my place in line. After all that now, I can say that I am happy that I was able to transfer my services at Tresco onto the waiver so everything I was receiving would stay the same. I am happy with my caregivers, I love my job, and I love having a place of my own. The wait was long but I am happy I am finally there. I hope to continue learning and meeting new people in my community.

**I am Waiting - Cynthia**  
**Albuquerque, New Mexico**  
**Bernalillo County**



My name is Cynthia and I am a 43 year old with autism. I have lives on my own for two and a half years at Silver Gardens in an apartment. I have also worked at the New Mexico Center for Self Advocacy for four years. I am doing pretty well for myself and have a lot of long term goals such as continuing to successfully live on my own, and do some traveling.

However, there are obstacles that have made it harder to achieve my goals and completely fulfill my goals. I originally heard about the DD waiver from other people in the disability community. I have been waiting six years for services. I have some supports such as medications that I can take for certain mental health issues. However, I am currently unable to see a counselor or get any more mental health services. I'm not too sure about some of the other services, but even have somebody to support me and help me out with things when I need help would play a big role in making my life easier. Having someone to talk to about what I am going through would go much farther than simply taking medicine and hoping any issues go away on their own. Even something as simple as getting a ride when I need to do a lot of grocery shopping at once or need to go somewhere and cannot access the bus would be helpful at night.

However, right now, it's hard. I have to rely largely on myself for support even when I would like to be able to have someone help me through tough times. It's hard because I have issues that I simply don't want to talk about with any average person. I need to really talk to someone who can understand what I am going through and can help me. Being in a situation where I am on SSDI makes it hard too. I would like to get off of SSDI eventually, but I don't know when that is ever going to happen because they keep us stuck. Being on SSDI and trying to make a living at the same time is hard. I cannot make too much money or I could lose it and that bugs me. Being afraid of losing it is hard. I want to make a better living.

The DD waiver services would help me with that and deal with the emotions that trying to make a living on my own and navigating through mental health issues brings up. Finally, I want to say stop people from waiting for services. They don't want to wait for services anymore. They are sick and tired of waiting. It does more harm than good. You wouldn't want to be kept waiting. Please help us end the wait and get the help that we need to meet our goals and live a good life. Please support funds for Developmental Disabilities Services and end the wait for thousands of children and adults with developmental disabilities and their families in New Mexico.



**I am Waiting - Elijah**  
**Silver City**  
**Grant County**



Who knows what may have been had he had access to services sooner; and who know how long we will still have to wait – or if there will be a DD Waiver at all by the time he actually comes up for allocation. Las I checked the wait had gone to 13 years in our area. This means, because of the year he lost, he should be 16 by the time he is finally allocated, a little late for intensive speech or behavior therapy, but essential nonetheless. Still, he was 2 when we initially applied and he will be 16 when (or if) he is finally allocated.

This state seems to have left these vulnerable children and their families to fend for themselves, lingering on endless waiting lists with the promise of service that never materializes, and now, it seems they'd like to go one step further and ignore them altogether. They are not going away. Kids like mine are healthy, and they are growing in number; the rates of autism identified in the schools have gone up and continue to grow. This is not a money issue, it is not even a political issue – it's a human rights issue. Children with special needs are not something to bargain over (or with), they must be taken care of; the Home and Community Based Services Waivers were intended to do this – to take care of these vulnerable children in their own homes and communities. I shudder to think of the challenges the state will face if families are unable to care for their special needs children what will happen as the rates of autism and developmental disabilities increase with no viable solutions in place to care for them. The current systems of per-capita allocation, waiting lists, and blaming the families or accusing the victims must come to an end. People suffering, and further cuts are not the answer.

**Are you or a family member waiting for services?**

**Share your story here.**

*Call the Arc of New Mexico today at 505-883-4630 or Toll Free 1-800-358-6493.*

*You can also email Carmen Garcia @ [cgarcia@arcnm.org](mailto:cgarcia@arcnm.org).*

*Check out our website at [www.arcnm.org](http://www.arcnm.org).*

***End the DD Waiver Waiting List Campaign funded by  
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