Community Members Testimonies

社区成员的故事分享

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Shi Shuo的故事

大家好!

我叫Shi Shuo Huang，今年32岁，是一名自闭症人士。

我平时在 AHRC 日间项目参加活动，也经常参与 CPC 举办的各种活动。对我来说，CPC 不只是一个提供服务的机构，更是一个让我感到被欢迎、被理解、被接纳的地方。在这里，我可以做真正的自己，也获得了学习、成长和参与社区的机会。这些经历，改变了我的人生。

今年早些时候，我跟随 CPC 一起前往纽约州首府奥尔巴尼，为残障人士发声，参与政策倡导。这是我第一次参加这样的活动。我和其他自我倡导者、家长以及社区伙伴一起，向政府表达我们的声音。这次经历让我明白，我的声音是有价值的，我也可以为改变社会贡献自己的一份力量。

随着年龄增长，我越来越常思考自己的未来。和许多残障成年人一样，我想要的不只是服务，更希望拥有持续学习的机会，能够真正融入社区，过上有意义、有价值的生活。

我知道，很多家长都担心孩子长大以后的未来，担心当自己年老以后，还有谁能够继续支持他们。因此，像 CPC 这样的机构对我们来说非常重要。他们不仅提供服务，更帮助像我一样的人建立自信、找到自己的声音，与社区建立联系，也让我们对未来充满希望。

对我来说，站在这里讲话并不是一件容易的事情。但我和大家一样，也有梦想。我希望社会看到我们的能力，而不仅仅看到我们的障碍；我希望每一位残障人士都能够拥有归属感，受到尊重，并有机会发挥自己的潜能，实现自己的梦想。

最后，我要感谢 CPC 给我今天这个分享的机会，也感谢在场每一位愿意倾听我们故事的朋友。

谢谢大家愿意倾听来自自闭症人士的声音。

谢谢大家!

Shi Shuo's Testimony

Hello, everyone. My name is Shi Shuo Wong. I am 32 years old, and I am a young man with autism.

I usually attend the AHRC day program. And I also participate in many activities organized by CPC. For me, CPC is more than a place just organizes programs. It is a place where I feel welcomed. Where I feel understood. And where I am encouraged to be myself. They give me opportunities to learn, to grow, And to be a part of my community. That has made a big difference in my life.

Earlier this year, I traveled with CPC to Albany. We went to advocate for people with disabilities. I stood alongside other self-advocates and families. It was my first time participating in something like that. And it changed me.

It showed me that my voice matters. It showed me that I can help make a difference.

As I get older, I think a lot about my future. Like many adults with disabilities I want more than just services. I want opportunities to continue learning. I want to be included in my community. And I want to live a meaningful life. I know that many families worry about the future. They worry their children become adults. They worry about who will support them. That is why CPC are so important. They don't just provide services. They help people like me build confidence. They help us find our voice. They connect us with our community. And they help us believe in our future.

Speaking is not always easy for me. But I have dreams, just like everyone else. I hope people will see our abilities, not only the disabilities. I hope every person with disabilities has the opportunity to belong. To be respected. And to reach their full potential.

I want to thank you CPC give me this opportunity to speak today, I want thank you everyone here to listening our stories.

Thank you for listening the autism's voice.

THANK YOU!

Xin的故事

大家好，我是两个自闭症孩子的妈妈。

我的大儿子今年12岁，是中度自闭症；小儿子10岁，是重度自闭症，同时还有癫痫、先天性肾病、睡眠障碍和行为问题。很多人看到的是孩子需要照顾，但很少有人真正了解，一个照顾者每天要面对什么。

我的一天，几乎从睁开眼开始，就一直在照顾孩子，没有真正下班的时候。小时候，家里几乎每天都像战场。刚把客厅收拾好，转身又发现孩子把衣柜里的衣服全部拉出来；刚清理完，又要处理尿床、换床单、收拾残局。最难的是晚上，小儿子经常凌晨一两点醒来，一直到四五点才睡。我不敢睡，因为他可能会跑出家门，也可能会接触危险物品。我已经记不清有多少个夜晚，是几乎没有完整睡过觉的。

后来，我找到一份兼职，希望能多少减轻家里的经济压力。可是，小儿子需要频繁看专科医生，学校也经常因为各种原因让我提前把孩子接回家。有一段时间，一周五天，几乎有四天都会接到学校电话。我没有办法继续正常工作，最后只能辞掉工作，成为全职照顾者。

让我最难忘的一次，是小儿子因为癫痫住院。医生安排他住院两天，连续做24小时脑电图检查（EEG）。作为妈妈，我必须一直陪在医院。但家里还有一个同样需要照顾的自闭症孩子，不能来医院。我们在这里没有亲戚，也没有家人可以帮忙，而我先生的工作又很难请假。最后，为了照顾大儿子，我先生只能辞掉工作。那一刻，我真的觉得，一个家庭在面对突发医疗状况的时候，原来可以这么无助。不是我们没有努力，而是当照顾责任全部落在一个家庭身上时，几乎没有任何缓冲的空间。

后来，我虽然不用上班了，但经济压力变得更大。每天除了照顾孩子，还要陪哥哥学习。别人二三十分钟能完成的作业，他常常需要两三个小时。在照顾哥哥的时候，我又会因为没有足够时间陪伴弟弟而感到自责，觉得自己什么都做不好。

长期的睡眠不足、照顾压力、经济压力，还有对孩子未来的担心，一点一点累积，让人几乎没有喘息的空间。有时候，那种疲惫不仅仅是身体上的，更是心理上的消耗。我甚至曾经想过：“是不是带着两个孩子一起去天堂，就不用再这么辛苦了。”我知道这句话听起来很沉重，但我相信，很多长期照顾特殊需要孩子的家长，都曾经在极度压力下有过类似的绝望时刻，但很少有人会主动说

出来。

今天我只是想让大家知道，我们这样的家庭，真的一直都在努力坚持。只是有时候，我们也需要有人接住我们.

Xin's Testimony

Hello everyone.

I am the mother of two children with autism.

My older son is 12 years old and has moderate autism. My younger son is 10 years old and has severe autism. He also has epilepsy, congenital kidney disease, sleep disorders, and significant behavioral challenges. Many people see that our children need care, but very few truly understand what a caregiver goes through every single day.

From the moment I open my eyes in the morning until I finally go to bed at night, I am caring for my children. There is never a real end to my work. There are no days off.

When my children were younger, our home often felt like a battlefield. I would finish cleaning the living room, only to turn around and find that my son had pulled every piece of clothing out of the closet. After cleaning that up, I would have to deal with bedwetting, change the sheets, and clean everything again.

The nights were the hardest. My younger son would often wake up at one or two o'clock in the morning and stay awake until four or five. I couldn't sleep because I was afraid he might wander out of the house or get into something dangerous. I have lost count of how many nights I went without a full night's sleep.

Later, I found a part-time job, hoping to ease some of our family's financial burden. But my younger son needed frequent appointments with specialists, and the school often called me to pick him up early. There was a period when, out of five school days, I received calls on almost four of them. It became impossible to keep working, so I had no choice but to quit my job and become a full-time caregiver.

One experience that I will never forget happened when my younger son was hospitalized because of his epilepsy. The doctors admitted him for two days to complete a continuous 24-hour EEG. As his mother, I needed to stay with him at the hospital the entire time. But at home, I still had another child with autism who also needed constant care and could not come to the hospital. We have no relatives or extended family here to help us, and my husband's job made it very difficult for him to take time off. In the end, my

husband had to quit his job so he could care for our older son.

That was the moment I realized just how vulnerable a family like ours can be during a medical emergency. It wasn't because we hadn't tried hard enough. It was because when all of the caregiving responsibilities fall on one family, there is almost no room for anything unexpected.

After I stopped working, our financial situation became even more difficult. Every day, in addition to caring for my children, I also had to help my older son with his schoolwork. Assignments that might take another child twenty or thirty minutes often took him two or three hours. While I was helping my older son, I constantly felt guilty that I wasn't spending enough time with my younger son. I often felt like I was failing both of them.

The chronic lack of sleep, the endless caregiving, the financial stress, and the constant worry about my children's future all built up over time. Eventually, it felt like there was no room left to breathe.

Sometimes the exhaustion is not just physical—it is emotional.

There were moments when I even found myself thinking,

"Maybe if I took my two children with me to heaven, we wouldn't have to struggle like this anymore."

I know those words are difficult to hear. But I believe many parents who have spent years caring for children with significant disabilities have experienced moments of profound despair like this, even if very few of us ever say it out loud.

Today, I simply want people to know that families like ours have never stopped trying. We continue to do everything we can for our children.

But sometimes, we need someone to catch us when we are falling, too.

Kaiming的故事

大家好，我叫 Kai，我的女儿 Charity 今年三岁。她患有一种罕见的遗传疾病——AUTS2 综合征。这种疾病会导致全面性的发育迟缓和智力障碍。除此之外，她的身体状况也十分脆弱，还面临视力、骨骼、消化系统、神经系统和肌肉等多方面的健康挑战。

今天，我非常荣幸能够在这里分享我作为一名特殊需要儿童家长，以及一位新移民，在一个完全陌生的体系中一路摸索前行的经历。为了节省时间，我想用三个方面来概括我们一路走来的挑战。

第一，是巨大的心理压力。

当我得知女儿的人生将与我曾经想象的完全不同——她不会拥有一个健康、普通的童年，而是要面对长期的医疗、身体和发育上的困难时，我的内心彻底崩溃了。我花了将近两年的时间，才真正接受 Charity 将终身面对智力、身体和医疗方面的挑战。我相信，很多特殊需要孩子的父母都会经历同样的阶段，不断地问自己："为什么是我？为什么是我的孩子？"那是我人生中最黑暗的一段日子。但后来，我慢慢明白，**接受，并不代表放弃。**接受，是学会继续向前，成为女儿真正需要的那位父母。当我跨过了这道心理关卡之后，我把几乎所有的时间和精力，都投入到帮助 Charity 成长当中。

第二个挑战，是面对一个极其复杂的服务体系。

EI、CPSE、OPWDD、Waiver、HCBS、DOE、DOH、Care Manager、CAS、CANS……这些缩写，对我来说，每一个都像进入了一个全新的世界。每一个机构都有不同的申请表格、不同的资格要求、不同的等候名单，以及不同的办理流程和时间。很多时候，我感觉自己需要一张地图，才能知道下一步到底应该联系谁。值得欣慰的是，如今 Charity 的情况已经有了很大的进步。她即将结束早期干预（EI）服务，并将在今年九月正式进入学校开始新的学习生活。

第三个挑战，是语言障碍与文化差异交织在一起所带来的困难。

要用第二语言去理解医疗术语、教育评估、保险文件以及政府资料，本身就已经非常困难。而 Charity 每天接触的医疗名词更是数不胜数，例如：内斜视（Esotropia）、第六对脑神经麻痹（Sixth Nerve Palsy）、静默性误吸（Silent Aspiration）、胃造口（G-tube）、胃空肠造口（GJ-tube）、鼻胃

管（NG-tube）、阿托品（Atropine）、踝足矫形器（AFO）、超踝足矫形器（SMO）等等。即使我能够看懂这些英文单词，我也常常不知道它们真正代表什么，更不知道下一步应该怎么做。但后来我发现，**语言并不是最大的障碍。**真正更大的挑战，是学习一种完全不同的文化，以及如何与这个体系互动。

我从小在中国长大，被教育要尊重专业人士，相信权威，不要轻易提出质疑。可是来到美国之后，我才慢慢了解到，这里的制度期待家长主动发问、主动要求评估、在必要时提出不同意见，并且一路为自己的孩子积极争取权益。然而，只有极少数的人会教新移民家长如何做到这些。回顾过去三年，我非常感谢一路上帮助 Charity 成长的医生、治疗师、老师以及各个服务机构。但与此同时，我也会想到一路上认识的许多移民家庭。他们同样努力摸索这个复杂的服务体系；同样学习着一种对他们来说完全陌生的文化；同时，还要承受照顾特殊需要孩子所带来的巨大心理压力。

没有任何一个家庭，应该独自走完这段旅程。

无论您是一位家长、一位教育工作者、一位医疗专业人士、一位政策制定者，还是社区中的一员，我们每个人都肩负着属于自己的责任。人们常说：“养育一个孩子，需要整个村庄。”而对于特殊需要儿童来说，我们需要的是一个更强大的村庄。一个能够提供信息的村庄；一个能够给予支持的村庄；一个愿意倾听的村庄；更是一个始终相信——**每一个孩子，都值得拥有实现自己最大潜能机会**的村庄。

我真心希望，未来每一位刚刚收到诊断结果的新移民家长，不需要再花上几个月，甚至更长时间，才知道该从哪里开始。而是在第一天，就能够遇见一个愿意陪伴他们、引导他们前行的社区。因为，如果不是我们，那会是谁？如果不是现在，那要等到什么时候？

谢谢大家。

Kaiming's Testimony

Hi.

My name is Kai, and my daughter, Charity, is three years old. She was born with a rare genetic condition called AUTS2 syndrome, which is characterized by global developmental delays and intellectual disabilities. Beyond that, she is medically fragile, facing challenges with her vision, bones, digestion, nervous system, and muscles.

Today, I'm honored for the opportunity to share my journey as the parent of a child with special needs—and as a new immigrant learning to navigate a completely unfamiliar system. To keep this short, I will share 3 challenges as a whole.

The first challenge was the overwhelming emotional stress.

When I realized that my daughter would live a very different life than I had imagined—not a healthy and ordinary childhood, but one filled with medical, physical, and developmental challenges—I was heartbroken. It took me nearly two years to truly accept that Charity would face lifelong challenges mentally, physically, and medically. I think many parents of children with special needs go through the same painful stage of asking, "Why me? Why my child?" That was the darkest period of my life. But over time, I learned that acceptance didn't mean giving up. It meant learning how to move forward and become the parent my daughter needed. Once I have overcome this barriers I used all my time and energy to help Charity.

The second challenge was navigating an incredibly complex service system.

EI, CPSE, OPWDD, Waiver, HCBS, DOe, DOH, CM, CAS, CANS, each term sound like a brand new world to me. Every agency seemed to have different paperwork, different eligibility requirements, different waiting lists, and different timelines. Sometimes it felt like I needed a roadmap just to figure out who to call next. Today, Charity is in good shape now. She will transition out from EI services and ready to start schooling this September.

The third challenge was the combination of language barriers and cultural differences.

Understanding medical terminology, educational evaluations, insurance paperwork, and government documents in a second language was already difficult. Again, infilled estropia, 6 nerve pyslse, silence aspiration, G-tube, GJ-tube, NG-tube, Atropin, AFO, SMO, are the medical conditions associated with Charity's daily life. Even when I understood the words, I wasn't always sure what they meant or what I was supposed to do next. But language wasn't the only barrier. The bigger challenge was learning an entirely different way of interacting with the system.

Growing up in China, I was taught to trust professionals and not question authority. In the United States, I gradually learned that parents are expected to ask questions, request evaluations, challenge decisions when necessary, and advocate for their children every step of the way.

Very few would teach immigrant parents how to do that. Looking back on the past three years, I am incredibly grateful for the services and professionals who have helped my daughter grow. But I also think about the many immigrant parents I have met along the way. Trying to navigate the same complicated system. Learning a culture that is completely new to them. All while carrying the emotional weight of raising a child with special needs.

No family should have to walk this journey alone. Whether you are a parent, an educator, a healthcare professional, a policymaker, or a community member, each of us has a role to play. "It takes a village" For children with special needs, it takes an even stronger village. A village that informs. A village that supports. A village that listens. And a village that believes every child deserves the opportunity to reach their fullest potential.

My hope is that the next immigrant parent who receives a diagnosis won't have to spend months figuring out where to begin. Instead, they'll find a community ready to guide them from day one.

Because if not us, then who? If not now, then when?

Thank you.