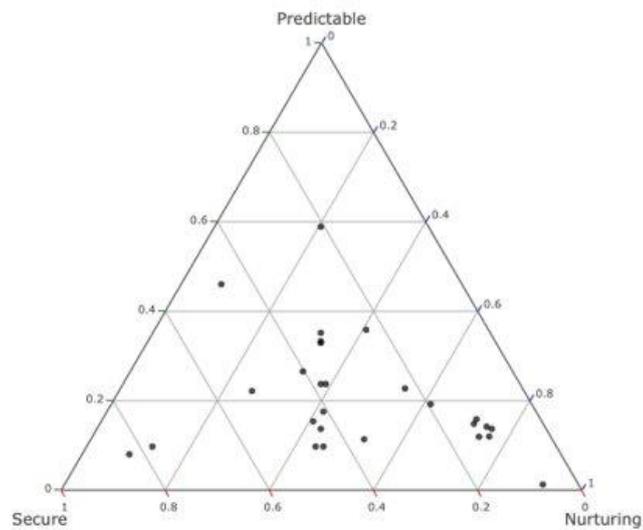
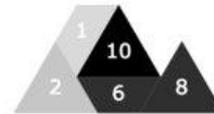


# Maternal Child Health Domain: Child or Adolescent with Special Health Needs – 33 Stories

## Homelife\_Pos

The family's homelife felt...

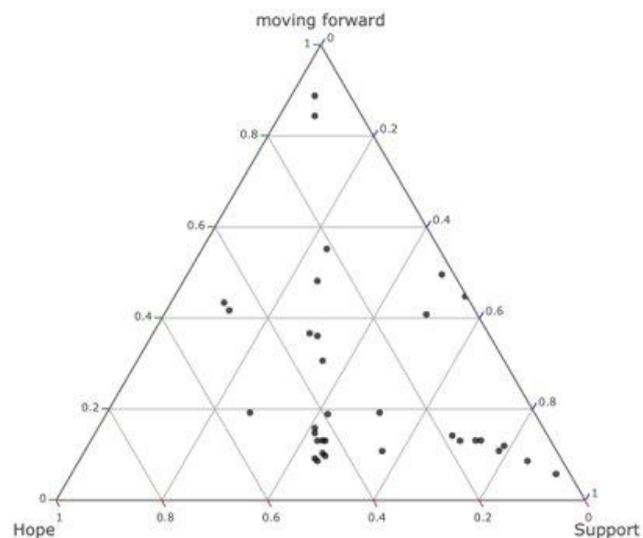
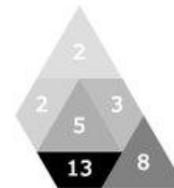
- Secure
- Predictable
- Nurturing



## Things got tough

In the experience you shared, when things got tough, what helped the family get through?

- Hope for the future
- Gritting my teeth and moving forward
- Support from others



### **illerate in KCK (709)**

My son is a student attending Kansas City Kansas Public Schools/USD500. My son, is entering sixth grade and reads on the first grade level. My son is a graduate of most of the early intervention programs available in Wyandotte County. He was enrolled in Parent as Teachers at birth. At eighteen months he was speaking only a handful of words so he was referred to Infant Toddler Services (ITS) where he received visits from speech pathologists and other specialists until the age of three when he aged out of ITS and was evaluated and accepted at the KCK Early Learning Center for the Tiny K program. That same year my husband and I took HIM to KUMC Center for Child Health Development to be evaluated for Autism Spectrum Disorder. We left the evaluation with a diagnosis of Global Developmental Delay not Autism. We were advised to share the results with the school and continue doing what we were doing. Which is exactly what we did. Our son went to school, he played at recess, and brought home drawings and keepsakes, and a few years later he even helped us welcome a baby sister. My husband and I attended every IEP meeting and Parent Teacher Conference. We offered support and reinforcement at home by communicating with our classroom teachers, special education teachers, and generally everyone in our neighborhood school. Our family attended school activities, concerts, field trips and joined the PTA. You name it we did it. Every year we were assured that our son was progressing. That the school was offering all the resources and support available. However, something would still keep me up at night researching trying to find what could help my son. Wondering what was wrong with him. Why was he not reading? In 2015, our son was in the second grade, after another long night of internet searches I sent an email to his school IEP team asking about Dyslexia. I specially asked if the school district tested for dyslexia. This question was met with surprising ambiguity. Comments of uncertainty and even silence. I do not have a background in elementary education and I struggle to understand the overall school jargon; MAP verse KAP testing, accommodations verses modifications. What little I know has been self-taught by hours of researching online. Overall, the school's response was more of the same thing. Offers to send books home, statements of how they will work with Antonio in the classroom. Nevertheless, I received no clear answer about do they evaluate for dyslexia. However, the question of Dyslexia kept returning to me until I finally just bit the bullet, in October of 2016, and paid to have our child be evaluated for dyslexia at Children's Mercy Hospital. Eureka! Children's Mercy Hearing and Speech diagnosed our son with six language based delays one of which is Dyslexia. This felt both overwhelming yet thrilling. Thrilling because we felt that finally we had the diagnosis that would get our son the help he needed. We shared his

medical diagnosis with the school and scheduled an IEP team meeting to discuss how to implement the medical recommendations. However, yet again, we were met with ambiguous statements about reading delays verses dyslexia, reading assistance verses structured reading programs; medical diagnosis verses educational evaluations and resources available in the building. However, I still naively trusted that armed with the official medical diagnosis my son would receive all the support afforded from the Kansas City Kansas School District. That his diagnosis would open doors for educational supports that have been peer reviewed and proven to increase academic achievement and success. Sadly, this has not been the case. This diagnosis has become our family's burden. I have found myself having to educate the educator's that dyslexia is more than writing in reverse. I have struggled to find affordable and trained tutors; I have taken countless hours off work to attend weekly therapy sessions at Children's Mercy. I have had to decide if we go on vacation or do we pay for summer tutoring? Do we go to the movies or do we pay for a new therapy session? I have leveraged friends and used family members to make connections or seek advice from people in the know. We had our child evaluated at the private dyslexia school and he was even accepted for admission to begin the fall of 2017 but who can afford \$25,000 annual tuition? I have joined associations, Facebook support groups, applied for scholarships, and on the hardest days I contemplate moving out of district. I think about moving so that my son can receive the support he needs to learn how to read. During my most eye opening IEP team meeting, February 2018, I specifically requested that a teaching approach proven to help dyslexics learn to read and to my shocked surprise the school district refused this service stating it was not available in his building. When I asked if this program was offered anywhere in the district and/or within the special education cooperative I was told this information was unknown. I listened as the school principal offered to write a grant to buy the curriculum and look for a willing teacher to take the training. And all I heard was more wasted time, waiting! Waiting for someone, anyone to offer my son the resource he needs before he gives up on school. When I set an IEP goal to increase his reading level at the end of 5th grade to 2nd grade level (increase from level F to L) the IEP team members all gasped oh that's too hard. they said. I couldn't help but think it wouldn't be if the school district used the proper reading program designed for children with dyslexia. I couldn't help but be enraged when the school district refused because of money. Because no teacher was trained in the entire District. I felt like shouting that my son is going into fifth grade and he reads on a first grade level! Does no one see this as an issue? For the past 15 months I have been involved in an unfair David and Goliath battle with an agency that

receives over \$200 million dollars from the very taxpayers the school district has decided to fight against providing appropriate services and remediation. The unbalanced fight in which a strapped for cash school district wastes valuable dollars on sending their attorneys to IEP meetings rather than investing in needed teacher training and appropriate dyslexia interventions. Unfortunately, KCKPS school district has not only failed my son in not teaching him to read. It has recently come to my attention that District wide KCKPS only has 14% of its grades 3-12 students meeting the state PROFICIENT ELA level (Level 3).

[https://www.boarddocs.com/ks/kckps/Board.nsf/files/BB34AB70C889/\\$file/StateAssessmentProjections%20PPT.pdf](https://www.boarddocs.com/ks/kckps/Board.nsf/files/BB34AB70C889/$file/StateAssessmentProjections%20PPT.pdf)In closing, I have been fortunate to find a private dyslexia tutor for my son to finally receive effective remediation in teaching him how to read. However, I know that unfortunately this is not available for many of the students attending KCKPS.

### **Grateful for what was available, but think there could be more done to support families in KS. (2820)**

I had premature twins with serious health issues when they were born. One daughter almost did not live and suffered brain damage. We do not have family in the area to support us. Although Rainbows United has been our most helpful resource over the years, I feel there have been many times we are just surviving. One struggle is finding additional therapy options outside the school system, and we live in a big city! Another struggle is finding quality childcare that serves healthier foods. I also have often wished we could have been formally connected with other families who have had similar experiences, earlier on in our journey.

### **Speech issues (740)**

My son was having speech issues. I took him to a screening at our local school district. Through the screening he was able to get the services he needed prior to him entering kindergarten.

### **Screening/Evaluation (894)**

Our son did not pass his three-year well visit evaluation, which I think was similar to the MCHAT. He was able to get into our local public school district for a screening within five days of his third birthday; however, it took us four months to get a call back from Children's Mercy to make an evaluation appointment and a month more to get seen for a screening. The waiting was so hard, but the support from the school district helped us manage.

### **Mental Health Struggles for People of Color (2381)**

A few years ago, my son was diagnosed on the autism spectrum. We didn't (and still don't) have a lot of support in the community. He was already a junior in high school. We were told that he scored high on the chart when he was in middle school but were also told that we didn't need to worry about it. Even though I questioned it several times through the years, no one really helped us until we got to KU Mental Health. It seemed like we were just going through the motions before then because we didn't understand what it was like for him. We still don't somewhat but we're learning how to cope with it better.

### **Mental Health Service Gap (918)**

We currently have several families who are just surviving. They are in need of mental health services for their child(ren) and families and it is a 45-minute trip each way to get the services. It requires them to take time off work also and this is very hard for them as they work shift hours or minimum wage jobs. The families have a child or children who have significant ACEs and the parents are struggling with supporting them.

### **Success of a new family. (1018)**

A family I serve recently moved to our area from California. They are living with Grandparents and do not have health insurance, a medical provider, or prek for their children. Resources were shared during our visit and appointments made for medical, application for Kancare, and enrollment in school. The family now has access to all three with the help of our agency. They are also receiving behavior help for their children with our Triple P program. The child on and IFSP has also made significant gains with his speech and language.

### **The I/DD Waiver Wait List Nightmare (1030)**

Our family recently received news that has us bracing for survival mode in the next year. Our son, who is completely deaf and blind as a result of being born 14 weeks premature, was put on the I/DD waiver wait list in [Year]. We were shocked and appalled to find out a couple months ago that after 7 years on the wait list, he is still far from the top. Our son will turn [age] next March and will no longer be able to attend the transition program at KSSB. Without the I/DD waiver, we have no way to access a day service program for him at that time, and neither my husband or I can afford to quit our jobs to stay home with him all day. This has put a lot of stress on us as we try to figure out how we will pay for whatever services he needs without any funding as well as our other two childrens' college educations.

### **Two Kids with Autism (1057)**

My two older children are both autistic. They are currently 9 and 7. Finding services for them and figuring out what to do to help them has been one of the biggest struggles of my life. I felt like I got help from no one. I felt so lost and helpless. After reading books and researching, I finally found services on my own. I had to hire private therapists. Looking back to when they were toddlers, I feel so let down by everyone in special needs services. They got basic speech and occupational therapy in preschool, but it certainly wasn't enough. No one ever made recommendations for me. I was forced to figure this out all on my own. I still feel like I don't know what all is out there. I always wonder what else I could be doing for them, how else I could be helping them flourish. This is certainly an area that needs tremendous amounts of work, in my opinion.

### **A crazy first years of life (1146)**

First few months of my life as a parent I found out my son was blind and he had a cyst on the brain and that can cerebral palsy all on one side of his body. Nobody could understand where everything came from. I had to go out of state for other doctors that knew exactly what optic nerve hypoplasia blindness was and I have to go to other cities to understand his cerebral palsy it was just very frustrating being a first-time mom with all of this stuff happening all at once I lost my job in the making because they could not understand that my son was my priority and I had too many Doctor visits. It was just very overwhelming and to this day I still have to apply for grants for his wheelchairs I get daycare assistance from the state because I need to still work to provide for my son I do not get food or cash assistance because apparently I make too much being a single mom which is impossible cuz I work for a school district. We make trips every other month to Kansas City for my son. My son has had three surgeries and he's only two two on his ears in one shunt placed for his cyst on the brain I had to take off 2 weeks of work for that which means really less funds. But I keep going I pushed through I wait on my mom and dad for a lot of help getting him back and forth to PT and OT three times a week. I work a full-time and a part-time job to help take care of my son and to buy the equipment he needs for his everyday life I can't go out and buy normal shoes I have to buy him a brake shoes which are just \$60 outrageous price but it's what I have to do in order for him to succeed and I would do anything for him. And only needs mom doesn't just give up he pushed through and fight and learn winnings to achieve the goals we need to achieve.

### **Relieved Mother (1148)**

A female of 2 year old was referred to Kid-Link based upon high levels of lead in her blood, which is an automatic qualifier for Part C Services according to State standards. When her Mother was contacted to arrange the developmental evaluation she reported a family history significant of medical problems for generations; including hearing loss and autoimmune deficiency. During the conversation, the Mother revealed her deepest concern for her daughter--that she did not act the same way as her other children did at her age. She stated that she just wanted to enjoy spending time playing with her daughter without the meltdowns. The mother was surprised that through Kid-Link, the Part C services offered support by professionals-therapists-specialized in early childhood who would travel to her home. By the end of the conversation, the Mother voiced relief that professional services were available at no cost to her and that there is hope for her daughter and her family to enjoy life with each other.

### **The disconnected therapists (1228)**

Starting services (SLP, VI, TOD, PT, OT ) for my deaf/blind child when he came home after a 7 month NICU stay due to being born at 23 weeks gestation. None of the therapists knew how to connect with a deaf/blind child. Progress was not being made.

### **Six Years of Looking for Help (1378)**

Our oldest son was 15 months old when I began to stay home full time with him while operating an in-home daycare. Over the next year, we utilized Parents as Teachers as we had concerns about our son's social-emotional development. He was hitting and biting children in my care, and it was frustrating to have to write notes home to parents as to why their children had fresh bite marks on their arms. I thought, Am I doing something wrong as a parent? Why won't my child play appropriately with other children? Because he was our first child, I had a lot of questions for our Parents as Teachers educator about developmental milestones, behavioral concerns, and nurturing his play skills. We were referred to Infant Toddler Services. After a home visit, it was determined that our son did not qualify for continued services with ITS. My family sought out a private play therapist who worked with our child and family on appropriate skills, creating an optimal play environment in our home, and seeking out play opportunities in the community. Still, some of the odd play behaviors persisted. At age 2-1/2, our son attended a church parents day out program. The director met with me more than once to share her concerns about my son's outbursts in class and unwillingness to engage with the children. At age 3, I had him evaluated at our local school district, and he

qualified for special education services, which he received until he began kindergarten. Throughout the kindergarten year, I received communications from his teacher and principal that he would say inappropriate things to classmates and that he did not know how to appropriately play with them. After his kindergarten year when I was pregnant with our third child, I took him to a private child psychologist who evaluated him and diagnosed him with Asperger's and Attention Deficit Disorder. Finally, after six frustrating years, we began to understand where our child was coming from. Had we not sought out these services ourselves, I am not sure our son would have received the appropriate diagnoses or services that ultimately helped him all those years ago. He is now 18 and about to begin college.

**Feel good work- early intervention is making a positive difference. (1649)**

Young child needs development assistants. He is being served by Russell Child Development Center. He was fit for hand splints and a vest. The splints allowed him to open hands and close his fist. While wearing the vest his movements are not as quick and more controlled. Feeding has improved and he has gained 10 pounds. Young child's parents are worried about him medically, and RCDC suggested the Attachment and Biobehavioral Catch-up program. Since starting the program, Mom talks about her baby and doesn't focus everything on medical diagnosis. She also had her first visit with RCDC and did not cry once. The young child is now reaching for toys.

**Mom is an advocate for her child (1652)**

Parents are great advocates for their children. I'm working with a family and the Mom was concerned about her child's head. Did they need a helmet. She made a doctor's appointment to check and the doctor did not think the child needed a helmet to help keep the head round. Mother made an appointment to have the child evaluated. The results came back and yes, the child needed to helmet. Not only did the child need a helmet, but it was a severe case. Mom is grateful for the early intervention assistance she is getting and support/encouragement to have the child evaluated.

**Next steps (1711)**

Our son is receiving services from RCDC. He is showing red flags for Autism and we are unsure of what we should do next. We are not legal citizens and I have court date for driving illegally without a license. Our RCDC provider is providing us with options to help us make the decision for what will be best for our son's development and our legal status.

### **Services for all immigrants (1715)**

I have older children who live in another state but my youngest daughter and I live with a friend in SW Kansas. This is where I could find work, and I have some family members. My daughter is happy and healthy but she does not talk or even try to talk. I heard about services that could be in our friend's home and the teachers come there to help her learn. I am worried about immigration enforcement, so I am not sure about continuing with the services when my daughter turns three, but the staff that works with us now does not seem to be concerned about my immigration status.

### **In need of healthcare and citizenship (1724)**

I am currently receiving services from RCDC for my son with multiple delays. My medicaid has lapsed for him and I need to reinstate his insurance. I also want to apply for citizenship, but was told by my lawyer to not access any government assistance for my family to increase my chances of being approved. I am unsure what to do next. My child is also potentially eligible for disability benefits due to his multiple/severe developmental delays. We need the insurance and cash assistance to survive, but we do not want to go back to Mexico. We are afraid.

### **Stuggling with a specialist (2496)**

My child has febrile seizures frequently. Due to living in a rural community with few specialist, we have few answers as to why this is happening. Our pediatrician referred him to a specialist in Wichita but driving that distance is difficult to do as a single mom because I would like help in the car with me in case something were to happen. The specialist never called for an appointment and I have not been able to get ahold of them. I am thankful to have my RCDC FSC to talk with this about and get recommendations from.

### **Grandparent raising child (1731)**

I am raising my Grandson and he is receiving services for speech delays. My daughter is unable to provide and care for him due to her battle with addiction. I did not plan to raise another child but am able to be successful in my parenting with supports from medicaid and developmental services. I wish I was able to help my daughter stay clean and sober, but she struggles to access the supports needed.

### **Diagnosing Learning Differences (1798)**

It was Fall of 1999. Lots of tension and community focus was on the Y2K ,“impending doom,” but we were struggling to understand why our bright, active, bubbly 2nd grader was acting out and resisting going to school. We couldn’t imagine it was because he was struggling to read and absorb the material he was offered. School itself was of such little help; for them, he fell in the range of acceptable scores and behavior. For us we were laser focused on the small, quotidian struggles and the rapid change in his presentation. It took outside help, including from a caring teacher in another school in our district to help unpack the testing analysis, and about three more years to finally get a diagnosis that would help us and our son get the sustained interventions he needed to be successful in school... and in life. All that navigation of the systems and the unfamiliar jargon took dedication, persistence and some fear for us to master... what would have happened to our son if any pieces of his immediate safety net had been less tightly knotted? I shudder to think.

### **Clarity makes the difference (1800)**

I am a home visitor serving families in Southwest Kansas through Russell Child Development Center. Many of my families do not speak English and some from Central America speak Spanish as a second language with a Mayan dialect as a first language. There are 22 Mayan dialects. Even with a Spanish-English translator it is very difficult for some families to comprehend the important details of a home visit if the Mayan language is their first language. Many times the children know English and Spanish but not much Mayan and as the years go by English takes priority for the children. Because of this language barrier, parents fail to understand parenting strategies, nutrition information, developmental milestones, and how to access community resources. One particular mother that I was working with was needing lots of help with difficult behavior issues from three of her four children. I had given Triple P positive parenting services to her one on one with a translator in Spanish. However, she was still not understanding key points of the strategies, partly due to cultural difference and partly because of words she did not understand in Spanish but only in Mayan. Fortunately RCDC was able to hire a Triple P coach that spoke her dialect of Mayan. When this home visitor worked through the parenting program with the family, the outcome was understood and much more effective. Also, there were other issues uncovered as the Mayan dialect was spoken, The family was then able to be referred to other agencies to address these issues. In the end the children benefited greatly and the home life was much improved.

### **Be the teacher- show young children how to interact. (1807)**

Provided Speech-Language Pathology services in a daycare providers home today. First time meeting this provider and in the beginning she was not aware of xxxxx services. I began seeing this kiddo at home with his family, but Mom shared her daycare provider had challenges with him. At daycare the little boy is having trouble playing. He rather play by himself or has fits (not sharing, hitting, etc.). Today I was able to show her strategies to introduce positive play with other children. Invite children in to play, help them find toys, praise children when they share and show them how to play together. By the end of the visit she was stepping in leading the encouraging words and interaction between the children that were giving her challenges.

### **It is critical children have access to hearing aids. (1842)**

My experience as a 1st time mother was both surviving and thriving due to congenital hearing loss after complications at birth for my child. Because our child had access to hearing aids before 6 months old she is thriving today. Without this opportunity we could be in a much different situation and we didn't know that at the time. There were many times when we were not certain if we'd ever hear the words Mommy or Daddy. While we are grateful to be able to provide what our child needs many children do not get what they need because insurance does not covers these lifetime costs. Children have a relatively small window to acquire language skills and for those who don't have access to hearing aids this can negatively impact development, language, educational and social/emotional.

### **Developmental Screening at Work (1760)**

A child was referred for the HealthySteps Program. During the initial interview, the HealthySteps Specialist recommended the child receive a developmental screening ASAP. The screening (ASQ-3) revealed the child had severe deficits in communication and social-emotional areas. The child was referred to RCDC's tiny-k program and further testing revealed the child could not hear out of one ear. Mom shares she is very happy she received early intervention for her son.

### **What Beetle truly needed. Early intervention and dedicated staff!!! (1222)**

Our daughter was diagnosed with Autism. For the first 3 years we were just surviving, everyday was very hard and long for both of us. We found our hope, our family survival when Early intervention came into our lives. With My family and Greenbush got our daughter to come out of her shell, she no longer had severe behaviors. She no longer needs medication. Our daughter graduated Mid-Year and has completed her first semester at K-State (actually living in the dorm rooms). When our daughter was first diagnosed I feared once her father and I passed, who would take care of her. With early development intervention and DD preschool it completely changed her life. I have not worried who would care for her, but have wondered on what major she will graduate university with, and what adventures she will have along the way! I could not ask for anything better to have happened than early detection and intervention by My Family and Greenbush!

### **“Outgrowing” Autism (1462)**

I was born in Israel, and when I was around 2 years old, I was diagnosed with Autism. But due to the top-notch childcare that's provided as a right by the Israeli government, as well as excellent private support, I was able to “outgrow” my Autism. My family was told by experts that my case was rare. I want my case to be the standard story for children with Autism as well as their parents. If I were to have been born in America, there's a greater chance that I would still have Autism today. That's unacceptable. And that's why I'm participating in this project.

### **Fighting for services (2688)**

My daughter with CHARGE syndrome had a feeding tube for 2 years. We worked very hard to get her to eat orally and after LOTS of hard work and therapy, we finally did it. It was a wonderful feeling knowing we were working toward getting the tube removed. But, once the tube was gone, we lost services. The state of Kansas doesn't have a medicaid program or waiver for children with multiple medical needs without a life saving device, so, once the tube was gone she was no longer allowed to stay on the TA waiver. Jackie is deafblind, she had to get a cochlear implant, wears a hearing aid on the other ear, has glasses. Has had open heart surgery and continues on heart medication as we wait for another surgery. She has very poor balance and she falls, needs lots of therapies weekly. She is scheduled for her second hip surgery in May, this will mark her 14th surgery in her 4 years of life. Yet, since she has no life saving device (g-tube, trach, etc) she doesn't qualify for medicaid. I quit my job as a registered nurse when she was born and I now stay home with her and I am her primary caregiver, the emotions run deep, and

sometimes I need a break. With medicaid, I was able to have a nurse watch her so I could sometime get away for my mental health, and other personal needs, that is no longer an option. We also had the medicaid as our secondary insurance and it helped cover a TON of her medical expenses, without it I worry we will fall into financial troubles. CHARGE is a lifelong condition and these needs will never go away. I personally know families who haven't even attempted oral feeds because they cannot afford to lose the medicaid if their child loses the tube. This is incredibly disturbing, our Kansas families deserve more.

### **Early Childhood Success (2486)**

A family in our local community was in survival mode, but trying hard to provide the best for their children. Their twin boys started preschool at age 3 and were nonverbal with the majority of skills extremely delayed (social, cognitive, language). School was very important to this family and the relationship between home and school became very important. These same two boys are in 1st grade now and are working at grade level and have learned great social skills and most importantly have consistency between school and home! Parents and teachers all agree that without early childhood intervention and the relationships built between school and home these boys would not be able to reach their potential! This story gives me goosebumps as an educator and I am excited about what they will now be able to achieve!!

### **Where do we go from here? (1508)**

We have a daughter who did not speak , she had speech delay so we had no idea until we had a home visit and from there we found resources for early intervention services

### **[County Name] child (2395)**

I saw a child that had no language when I started seeing him with infant/toddler. After a year he was putting two words together and saying more single words.

### **Gratitude for Services Offered (822)**

My oldest daughter (5.5) had serious health issues her first year of life. We were living in [STATE] at the time and although we received amazing services through Early Intervention (thanks to tremendous Social Workers at the hospital and doctor office explaining which areas of services to explore) the services after 3 were not great so we made the decision to move back to Kansas. Here in Kansas we have received amazing services through 501 and Early Intervention for my 2nd daughter. [NAME] (5.5) receives all 3 services, she attended [SCHOOL] last year and now she is at [SCHOOL]. I have been so pleased with the level of services she has received at both school. My youngest (2.5) is currently receiving Speech through Early Intervention and we have been incredibly pleased with the ease and level of services they've offered. When your child needs help (in any matter) it makes everything so much less stressful when the process, as it has been here, is easy and the services that you are receiving are actually making a difference.

### **Support is everything for our family (2676)**

We have a child with a very serious developmental diagnosis and co-occurring autism. When we first moved to another country and hadn't developed any care networks, our family was definitely just surviving. Having no support made us feel isolated and uncared for. Both my partner and I felt depressed, and we worried that it was affecting our older child too. Once we got a caseworker and some services, things changed dramatically. We felt part of the community. We felt hopeful. Behaviors started to change. Our other daughter began to make friends and do better in school. We spent more time together as a family because we were able to bring our daughter with special needs on outings she had previously been unable to attend.