FAMILY VOICES OF NORTH DAKOTA®

North Dakota Family Stories
The Importance of
Early Intervention Services
in North Dakota

Family Voices of
North Dakota
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Families are dynamic and cultures unto themselves, with different values and unique ways of realizing dreams. Together, our families become the source of our rich cultural heritage and spiritual diversity. Not all disability is obvious, nor all ethnic or cultural heritage discernable. These stories and images represent the many hearts in our Family Voices.

Purpose

Family Voices of North Dakota provides information and resources to families who have children and youth with special health care needs and disabilities. Many times that information begins at birth. It is important to us to share information on programs such as Early Intervention, so others may understand how important these vital services are for families.

A family situation can change from day to day, for these families, one never knows. Families want what is best for their child, they want to be able to go to work and stay employed and to be tax payers instead of tax recipients.

Information regarding services

Quote from Minot parent-"Parents and our children need and require the Early Intervention program to flourish, develop, and succeed. The program acts as a life preserver and brings hope to families like mine. It does much more than that though. It provides the aide and support that children like Olivia need in order to develop. "

Inside:

DISCLAIMER: The Comments and opinions expressed herein do not necessarily reflect the policy or position nor imply official endorsement of Family Voices of North Dakota, the funding agency or its working partnerships.

Hello. My name is Vicki. I have two terrific boys; one is 15 and a sophomore in high school; Aaron is 5, Autistic and receives Early Childhood Special Education.

Aaron was diagnosed, officially, at 17 months, but long before the official "word", I knew Aaron had some severe issues and learning disabilities along with his great abilities. I started to notice small things even at 3 months. His brain seemed to be moving at a much faster pace than his body. After a recommendation from his pediatrician, we sought out a specialist who could help, which in turn led us to Early Intervention Program. I remember calling the minute I had the phone number in my hands, it was such a relief to know people were there to help and a worry of how I would pay for such help was gone. Aaron was evaluated in our home and within the first week , I bet I met with a dozen people. For my family this was a crucial turning point in our lives. I now had speech therapists, occupational therapists, parent specialists, family advocate, DD case management and many more offering support, help and resources for our family. The word "specialists" for myself and Aaron was not used lightly. To have highly trained professionals come in my home seemed to good to be true. Along with all this I feel I became a "specialist" to in my own way, just by learning what all these people had to offer. The therapy and education Aaron received began to work and I was taught to take it "one day at a time". It definitely paid off ! Aaron was non-verbal and now is regaining his language. For Aaron a huge accomplishment; for myself to hear the word "mommy" again was a goal I was hoping for and I got my wish with the expertise help of all the people on Aaron's team. I knew right then education for Aaron was and is possible, anything is possible.

Autism affects 1- 150 children in the U.S. This is the fastest growing neurological learning disability in the U.S. Early Intervention is the only resource scientifically proven to have a positive affect on children with Autism Spectrum Disorders. Early Intervention is a special gift given to us for all the families who need this type of special care. I will never be able to thank and show how much I appreciate and treasure everything our family received from Early Intervention Services. My hope for the future is that Aaron will be able to be educated, independent and a productive member of our community which will reflect on how much everyone cared and contributed to his life.

Please make sure this program receives special attention and the growth that it so well deserves. Let us make sure the hard working people in this program receive the resources and the financial income to stay in North Dakota.
Vicki, Erik and Aaron Peterson

We are Nicole and Bruce Snyder, and want to introduce you to our 2 year old son, Tyler. Tyler is our only child, and was in St. A's in Bismarck after a full term, but rather difficult pregnancy. I ended up in the hospital during my seventh month with a very low white blood count.

Tyler was having respiratory difficulty shortly after birth, and began having seizures while he was still in the hospital. He was hospitalized for a month to get his seizures managed and respiratory issues taken care of before being able to come home.

My mom, Jane, who works in the business office of our local hospital in Harvey, told us that there were services to help parents with their babies.
She gave us the number and we called. Soon after, a case manager came to visit us and explain the process and services available. Tyler was eligible to receive Early Intervention services, and we have had weekly visits to our home from a home visitor since then.

We have appreciated having someone help us learn how to help Tyler and what to do to improve his progress. Tyler seems to really like having his home visitor come to "do things" with him. We will really miss that when he turns 3.

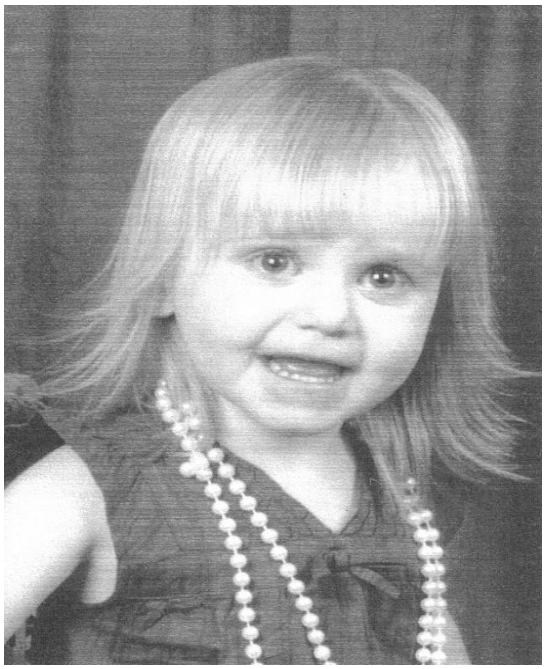
Staff have been easy to work with and have arranged home visits around our work schedule.

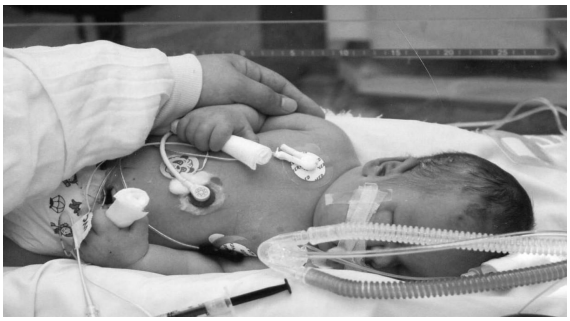
We as parents have felt supported and very much a part of Tyler's progress because visits have been in our home, where we and Tyler are comfortable.

"We worry about what a child will become tomorrow, yet we forget that he or she is someone today"
Stacia Tauscher

Hi—We are Scott and Pam Faul from Harvey, ND, and this is our story:

Phoebe was born at Trinity Hospital in Minot after a typical pregnancy. She came home after a normal hospital stay. After a few days, we noticed she had trouble breathing and took her in to be checked. One thing led to another and we ended up at Fairview University Children's Hospital, where, at 12 days old, she was diagnosed with hypoplastic left heart syndrome. That means she was born without a left ventricle. Here we thought we had a perfectly normal little baby, and at three weeks of age, she had her first open heart surgery. After a lengthy stay in Minneapolis, we were finally able to bring her home. The hospital had made the necessary contacts with the ND Department of Human Services so when we came home, Lynn Zimmerman, a case manager from South Central Human Services and Cindie Richman, the director of South Central Regional KIDS came to visit us. They explained the process and the early intervention services, and got the ball rolling so Phoebe would be able to get some extra help. She had to return to Minneapolis for a second surgery at 6 months of age, then again when she was a little over 2 years old. She recovered faster after each surgery, which helped us to get back home sooner. However, from all the time she spent in the hospital since birth, she had gotten behind in some of her motor skills and speech. Our home visitor, Melissa, came weekly to help Phoebe work on these areas, and to help us learn how to help her progress. The visits were always at our home, which was great. Phoebe was very sick for a long time and couldn't leave the house or be around many people. Whenever we needed something, our home visitor or case manager helped us get it. Phoebe has just turned 3 and entered Part B services. We had a tremendous experience with Early Intervention, and thanks to their help, Phoebe has almost caught up to where she should be!





"Children are one third of our population and all of our future"
-Select Panel for the Promotion of Child Health, 1981

Early intervention service in North Dakota is a fast downward spiral. Once you finally find out what is wrong with your child the services are ending without any plan for future goals. We found out about autism real fast and real hard. We also found out that services don't last long enough to let you get a grip on the diagnosis before they are shooing you out the door and you drop off the face of the earth. When your child turns 3 its see ya later, see ya again when your 5, when someone can pay for your services.

You are left dangling like a worm on a hook. There is no set curriculum for your child there is no plan there is just uncomfortable space. New families who are right where you were have no idea what to do, where to go and how to help their child so its up to the families who are still whip lashed to help them.

Being 3-5 age is hell. No support, no directory just chaos. Then when you do turn 5 its like "oh well you should of been doing this and that and now all these things are behind", but if there was planning, funding, staff to help with the 3-5 age, parents would not be so behind or helpless. They would of been able to help their child instead of standing by watching helplessly. If we want to really help kids in early intervention we need to CONTINUE to be there for them before they hit age 5 and hit public school. They need to be overly prepared than not at all.

Sonya Bull mother of two autistic children age 3 and 4

I have never appreciated a person or a group of people like the ones I have met here in Grand Forks. My Northeast Human Service person has given me the information the tools to make life easier to deal with. Every time I feel as though I have hit a brick wall in finding a diagnose for my son's disability my person will give me a new doctor a new name, a new program. She has left no stone unturned. There is not one person she has not brought to my house to meet. She continuous to bring new and exciting news to me every day about trying new things with my son. I never thought I would have a child with a disability but because of the wonderful team of people at Northeast my day is normal and so is my sons. I don't have to worry if there is someone else out there that can help my son because I know that Jean will find him or her. Thanks Pam Martin

I am Stephanie Becker. I'm married to Darrell. We have 5 sons...Josh 16, Ryan 13, Austin 10, Noah 5 and Joseph 2. Joseph has Down syndrome and he was also born with medical issues that have taken us out of state 3 times for surgeries. We live on a farm outside of Napoleon. There is never a dull moment around our place and IF there is it surely doesn't last long. That is alright though.

We first heard about Early Intervention in the hospital when Joey was born. My mind was all over the place back then and I just put it all on the back burner until we received a phone call from our case manager in Jamestown shortly after Joey was released from hospital after his first surgery. He introduced himself and explained the program and set up a date for a home visit. It was all overwhelming at the time but quickly became second nature to having someone come into our home a couple times a month and then eventually every week.

Living so far from our hospital which offers Speech Therapy, Occupational Therapy and Physical Therapy just wasn't working for me to drive so often. The cost of gas plus having all the other kids at home were big challenges. Joey had a ST, OT and PT evaluation every 3 months and still does today. It is a huge relief to be able to stay in our home where Joey is most comfortable and have the therapists come to us.

It is always great to get new ideas from them for ways to work with Joey. My biggest wish would be that we would be able to have more services in home. Another reason I don't like taking Joey to the hospital for services is because I don't want him picking up unnecessary germs. Joey is non-verbal right now and while he used to babble some he no longer does. If we didn't have to drive so far for ST I would take him. But traveling 85 miles one way just seems too much. It would be wonderful to have ST in home even 2 or 3 times a month instead of just 1 speech eval every 3 months. My friends in the bigger towns can't believe we don't get more in home services as they have so many. I hope that will change before Joey turns 3.

Hi. My name is Jane VanRay and this is my story. My family and I live in the rural community of Pingree, ND. My husband, Matt, and I have been blessed with two beautiful children; Alex and Kaydence. As residents of ND like many we farm. We grow the irrigated crops of corn, wheat, and soybeans, and also potatoes. Matt works hard to allow me to stay home to care for our family.

Kaydence is our newest family member. At six months of age she keeps us running. She likes to crawl around and try to do what her big brother is doing. Alex is two and lights up every room with his smile and large dimples. At 10 months old, during a Right Tracks screening, we noticed that Alex was not making developmental milestones in a timely manner. Shortly after the screening we were introduced to the Early Intervention Service. After many tests and trips to different doctors, Alex was diagnosed with a genetic disorder called Angelman's Syndrome in June of 2007.

In July of 2006 Alex started the services of the South Central KIDS Early Intervention Program (EI) in Jamestown. We do not have to worry about the distance because they come to us. Cindy Richman is the coordinator who works with a great team. We have also worked with Tina Dosch their occupational therapist. Lynn Zimmerman is our case manager. The person who we see the most of is Sandi Lies. I like to call her our infant developMENTOR. I highlight the mentor because that is what she truly is. She has been sent to help many families dealing with the difficulty of raising children with special needs. Through the EI she is able to coordinate all of Alex's needs during weekly visits. She has helped implement the Individual Family Service Plan (IFSP) for Alex. The IFSP is the blueprint for all of Alex's needs. IFSP determines the current medical status, level of development, strengths, weaknesses, Alex's goals and how the team will achieve these goals. Sandi coordinates the speech, physical and occupational therapy sessions. She takes what is done at these sessions and shows us how to do the activities at our home with common household items. (EI is able to provide some equipment if the family is unable to obtain it) The EI developmentor is able tell you what is out there and how to get it. EI has opened the door to many other services: Women Infant and Children (WIC), Health Track, Medical Assistance and many more. Most importantly Sandi has brought our family a support system. Sandi is someone that listens. She laughs when we laugh, cries when we cry and is joyful every new step that Alex takes no matter how tiny it may be. It is nice to have someone you feel comfortable talking to that can answer your most difficult questions that nobody else has experienced.

What is the most disappointing about the Early Intervention is that our family will have to be discharged on Alex's third birthday. I will miss the weekly visits the most. After two years Sandi has truly become a member of our family. I have not found anything that has not been beneficial to our family. The only thing that could have been different is that I wish we could have been enrolled sooner.

There is much more to say about how Early Intervention has helped our family. If you would like more information I am available by phone 701-285-3535 or e-mail jmvanray@hotmail.com.

My name is Victoria Erickson from Cooperstown, ND, and here is our story. Tim and I are the proud parents of Anna, 2 $\frac{1}{2}$, and Lars, 6 months. Lars was born at the hospital in Jamestown in February 2007. He came three weeks early and was in respiratory distress at birth, so he was transferred to Innovis Hospital in Fargo. He spent two weeks in their neonatal intensive care before he was released to come home.

The staff at Innovis contacted South Central Human Services and Early Intervention for us. We weren't home long, when Susie Heise from South Central came to visit us. She explained to us the services available through Early Intervention, and got us started on the paperwork for Medicaid. Soon we had visits from a physical therapist, occupational therapist and an education specialist. Each gave us many ideas on how to enhance Lars' development and progress. Heather, our home visitor, continued to come weekly to our home to monitor Lars's progress and give ideas to us on things to work on during the week. She also helped us adjust to having a child with a disability. She is wonderful!

The biggest challenge to early intervention services is that they are only able to make a home visit once a week. More time would be great! It's great that they come to our home where Lars is comfortable and familiar. When he turns three, I will miss the support and comfort of having the therapists come to our home and the opportunity that provides for them to give us ideas on how to continue to enhance his development. It would be nice if there could be some counseling offered to parents and family members when their new family member has a disability.

Without our caseworker, Susie, we would not have known what to do for our Lars. The paperwork and legal stuff she helped us with would have been overwhelming. The therapists have been so good to work with, too. Lars is doing great, and they have really helped me learn how to help my child. They give me great feedback on how we are doing and I would feel lost without them. As a new parent of a child with a disability, Early Intervention has changed our life. Because of Lar's involvement with Early Intervention, I have had two other families in our community ask me about the EI services, and they are both getting help for their children.

Our story…….

Lanie Jo was born to her proud parents 2/18/06 in Dickinson, ND. As first time parents, we truly thought our biggest challenge and accomplishment would be getting to the hospital on time, 75 miles away (from Slope County), in the middle of February, when it was well below zero to have her! We quickly learned differently.

We learned about the Early Intervention Program through a questionnaire in the hospital before Lanie was born asking us if we would be interested in their services. We started with the development screenings when Lanie was about 3 months. At our visit Lanie had some trouble with her head control and tracking of objects. These signs, along with her pediatrician's recommendations, led to a more complete screening when she was 6 months old by a team from the KIDS program. This evaluation concluded that Lanie did have development delays and was recommended to begin weekly therapy sessions with an interventionist.

The interventionists that have worked with Lanie have been very helpful and accommodating to our families needs. Lanie has received occupational, physical, and speech therapy weekly. She has also vision evaluations and follow-up consultation. The Early Intervention Program has provided us with many toys and tools to take home and use in our daily routines with Lanie. They have been a great help for specific tasks and exercises Lanie works on to improve her strength and balance.

Words can really not express the complete resource the whole Early Intervention Program has been to our family. If they don't have the answer to our questions right away (which they usually do) they find it. They have provided us with literature about how to address Lanie's special needs and many ideas to continue her therapy at home. As new parents we don't always know the development milestones and how to achieve them, the Early Intervention staff has always kept us on track and the given us steps to achieve our families goals.

Missi Baranko, the Experienced Parent at the Early Intervention has been our angel. From a listening ear to helping explain a doctor's diagnosis, she is always helping us. She has helped us understand the referral process, insurance issues, provided contact information for specialists, make appointments, and provided great parenting advice.

Lanie is currently 18 months and has taken her first 5 steps! She is wearing AFO's to help her walk and build leg strength. The Early Intervention has taught us how to use sign language with Lanie to communicate through her speech delays. Although we have been seeing a neurologist, we currently don't have a diagnosis for her development delays. But we are in the process of getting her into the University of MN to see a specialist and to hopefully get some answers for Lanie's situation.

The Early Intervention program has been a vital part of our family's life over the past year. They have given us awareness to Lanie's needs and the tools and resources to help with her continued development.

"If our American way of life fails the child, it fails us all."

-Pearl S. Buck

My name is Elizabeth Sides, and my daughter, Olivia, was born with an unknown genetic syndrome. No doctor has been able to figure out what she has yet, so they treat her symptoms. It is hard as a mother to watch your child being poked and prodded for the first two years of her life. At birth, the pediatrician noticed that she had an anterior atopic anus. However, nothing was done to fix it until she was 17 months old. At two months old, while I was feeding her a bottle, I noticed that was a problem with her eyes. Just before Halloween 2004, she was diagnosed with microthalmia and double iris colobomas in both eyes. In January 2007, her eye surgeon took this diagnosis away and said that she does not have this, but she does have uncolored cat-eye pupils and very bad vision. She also has only one kidney and renal reflux stage 3. Olivia has other physical characteristics, but none of which are severe. I say this and at the same time we do not know what she has. The geneticist said whatever she does have is even more rare than the diagnosis of cat-eye syndrome, and she was the 35th person in history to be diagnosed with that.

As for her developmental delays, Olivia has always been on the delayed side. She was behind in every milestone. Doctors were not sure if she would ever do things, but I always had faith in my child. Faith that anything was possible. A special kind of faith that I would come to treasure when our family moved to Minot, ND. As for the meantime, our days consisted of good ones and bad ones. Lots of stimulation and times when I wanted to just let her be. Something inside of me would not listen. It would not give in. Times were really frustrating in Vegas. I think mostly because it is a city that is full of all kinds of doctors and specialists. One would think there would be much more available for a child with special needs. Maybe there is. I do not know. Olivia was born July 21,2004, and we left Las Vegas on July 21, 2006.

She was part of Nevada Early Interventions. The waiting list was extremely long, so I was just all by myself until they got to my name. I felt so alone, and it did not really get any better in the program until the end. Her developmental specialists seemed to constantly change until the end. However, Olivia seemed to finally open up when a speech therapist was brought in to teach us to sign Exact English. The signing did help Olivia a lot though. It gave her a new found freedom. She was actually able to communicate with us for the first time. The therapist said to take it really slow, just a couple of words at a time until she learned them. Olivia was a pro though. Within one week, she knew 7 signs. Then 13 signs, she was on a role. Unfortunately, it was shortly thereafter that we moved. I knew we could keep going though. Man, with Minot Infant Development Program behind us, Olivia was soon going to turn into a completely different child. Hello world! Here comes Olivia Sides. From October to December, Wendy helped us sign and teach Olivia to speak more. Then on Christmas, we received our present, our Olivia found her beautiful voice. She has not stopped ever since.

Then we moved to Minot, ND. I was already skilled in what I needed to do upon arrival. So shortly after arriving, I was hunting down the Minot Infant Development Program. WOW! I was so shocked and surprised! Everyone came to my house within a couple of weeks and started the ball rolling. We did NOT have to wait?! I couldn't believe it. I was told everything from start to finish had to be done within 45 days! Talk about relief. I could just cry. We had spent the last two years going from specialist to specialist, and no one could give us any answers. But, here is a group of people willing to do whatever they can to get all the evaluations they need in order to get her into the program to get my baby back on track. Oh my gosh, after everyone left I just cried. I was so happy. It is like I finally knew why we were meant to be in Minot. I was not prepared for all of this, let alone what was to come in the months ahead.

The Minot Infant Development Program had Olivia set up with weekly home visits within 45 days. Immediately, Wendy Thomas, Olivia's Early Interventionist, started working with her. She even consoled me on my bad days, and helped me research medical information about Olivia. She was God sent. I couldn't believe how supportive she was. She came to our house like clock work every single week. Olivia was so in love with her. She taught Olivia new signs, worked on new activities that she could not do yet,and teaching Olivia communication skills. Wendy was awesome! I remember so vividly one day Wendy came to our house and I was so upset and I had been crying all night and morning. She had been working with us for a while now, and she knew me so well. When she asked what was wrong, I started crying trying to explain that Olivia expressed that she wanted to start potty training. Of course, Wendy was all excited about the huge milestone, but she knew immediately what my problem was. Olivia was 16 pounds and about 28 inches! I was not upset about the pull-ups. Forget those! I was devastated that my baby was way too short for the toilet and too short for the training potty (they make them for the AVERAGE size toddler)! Additionally, how does one get little ones excited about potty training? "Let's go to the store and buy some big girl panties!" Well, guess what. The smallest size panties and training pants that anyone makes are size 2T or 24 months. Wendy was so supportive. She told me to google "preemie panty," and she went back to her office and started searching for me too. I was so happy that she would go to all this trouble for me. Nonetheless, the searches were useless, but I learned a lot from Wendy that day. The internet can be very powerful resource, and I am not going through this alone.

After that meeting, Wendy got to thinking about our home, and how accessible it was for Olivia. She came back the next week, and we started talking about it all. Wow! Again, I couldn't believe that I had not thought of this stuff before. Olivia is really short, and she is a full-fledged toddler. Especially with her wanting to potty train, we really needed to consider accessible technology for Olivia. Unfortunately, now we are encountering problems that we never dreamed of or would have thought of before she came into our lives. You see, Olivia is a toddler ready to potty-train, climb stairs, turn on/off lights, open doors,

tricycles, and do just about anything and everything that other children her age do. However, she is extremely short and petite. Therefore, she cannot reach door knobs, rail, light switches, peddles, etc. Despite everything that Olivia has had to go through in her life so far, she has overcome everything. She is the toughest fighter I have ever seen, and she sticks to her guns. It would be a shame for something as silly as these things to hinder her development and independence. Wendy knew that, and she had begun the ball rolling for us. That was the first time I had heard about accessible technology. She made a few calls and told me that we could take Olivia's bicycle into town and have it made accessible for her to reach. Now my baby could ride her bike!

Wendy was always on top of everything with Olivia. She even got Julia involved when she was home. I was just so amazed, as well as my husband. We couldn't believe the progress and the support. My husband saw me changing. I felt like I was becoming a different person. Wendy became part of our family. I started sending her pictures and emails. I would call her during the week when Olivia would do something new or something would happen. In May, I remember calling Wendy to let her know that Olivia was put in the hospital for 105 fever. I told her I was so scared because the doctors couldn't figure out what was going on. She was so supportive. She wanted to know if we needed anything, and she called every day to check in on Olivia. To me that was going above the call of duty. It turned out to be pneumonia, and Olivia was fine. Wendy was just so genuinely concerned. We had never experienced that before.

Now, it is August of 2007. Everyone in the Infant Development Program has been amazing again. They started preparing Olivia and our whole family back in February for the big transition. They gave us our options. In April, they took us to the school and introduced us to Olivia's teacher and speech therapist. They even included our older daughter, Julia. We were all so excited! Then reality hit that when Olivia transitioned, she would no longer be a part of this amazing experience that we had loved and adored so much. Olivia heard us talking, and she got upset. Wendy and her soon to be teacher fixed the problem right then. Wendy was more than welcome to come and check in on Olivia whenever she wanted to. Well, Olivia became herself again. She started blossoming in the preschool room. I was saddened and worried and happy. All these old emotions started to surface again. Olivia had medical needs, communication skills she was still mastering, she was so small and petite. I think Wendy knew exactly what Dean and I were thinking. I also verbalized my thoughts, as well as my husband's, who had many issues with Olivia's special needs at the time. A couple of weeks later, Wendy called me and said she had an experienced parent, Dawn, whom she wanted to bring out. I was ecstatic! I think that it is so wonderful that people, like Dawn, are so willing to go and talk about their experiences. It helped me feel better, not because I know that she was in my shoes. But because she opened herself up to talking to me about anything I needed to talk about and answering any questions I had. It made the transition that much easier.

I do not have the words to express on paper exactly what the Minot Infant Development Program has done for Olivia and the rest of my family. Parents will travel to the ends of the earth for their child no matter what. My life has gone from being "normal" to being "my new normal." It is a life that one is not sure of. A life that can go from blissful to excruciating, and be both things all at once. It is a life who's pathway is unsure of, but not one moment or one thing in it is taken for granted. I would not change my life for anything in the world. Some people do not know how I do it, but the Minot Infant Development Program does, the Experienced Parent connection that the program gave me does, and my family and friends do. It is because of the program that I have the connections, support, and conviction that I didn't have before.

I believe that special children hold special powers. Meaning, they are teachers to us all. They have the power to teach us all compassion, hope, and love. To teach us all, family and strangers, to have compassion for all around us, to give us hope that anything is possible, and to love more than any of us have ever loved before. They teach us endurance and perseverance. No matter what is going on, these kids are the toughest kids I have ever met in my life. They don't give up, and no gives up on them.

The Minot Infant Development Program plays such a powerful, direct role in this lesson. US parents and our children need and require the program to flourish, develop, and succeed. The program acts as a life preserver and brings hope to families like mine. It does much more than that though. It provides the aide and support that children like Olivia need in order to develop. After all, if it was not for the Minot Infant Development Program, I don't think Olivia would be talking in sentences today. It is because of the program that Olivia is blossoming like a flower in spring. I have never seen her so happy. She can express herself with words, and she can draw, and she can walk up and down stairs like any other toddler! What more could any mother ask for! Especially considering she was not talking in November or climbing up stairs in March this year!

THANKS ALL TO THE MINOT INFANT DEVELOPMENT PROGRAM AND ALL THE MEMBERS AND SUPPORTERS ON OLIVIA'S TEAM!

Sincerely, Elizabeth J. Sides

Our son, Casey, was born 9 weeks premature. At 3 pounds, 4 ounces he spent the first 2 months of his life in the NICU at Altru Hospital in Grand Forks.

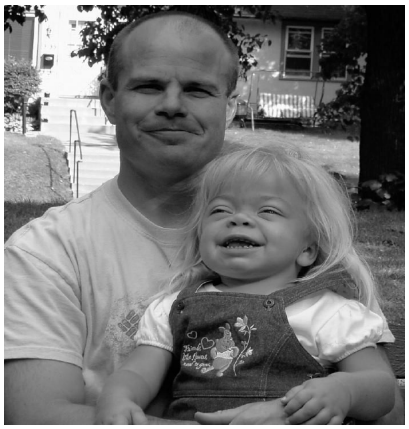
We were overwhelmed with the anxiety from day to day wondering how his health would suffer due to his prematurity. Once we had been reassured that he was ok physically we started to become concerned about his development in other ways. We were very concerned that Casey would be behind his peers as a baby and toddler because he came into the world earlier than he should have. The social worker from Altru told us about Infant Development.

Casey started seeing Reesa, his Infant Development therapist, soon after we brought him home from the hospital. She instantly put our fears to rest as she explained what her role would be in Casey's development as well as the other resources available to us through her. We were told about the importance of hearing tests and Casey was also seen by OT and PT. He suffered from torticollis and Infant Development gave us options for his treatment along with the proper referrals.

Casey will be 2 soon and he still sees Reesa every week as our schedule allows. He is thriving and shows no signs really of being premature. People ask us all the time how old he is and are surprised to hear that he isn't even 2 yet. Infant Development has stayed on top of making sure Casey is developing normally and doing all the age appropriate things he should be. We really feel that, without Infant Development, there may have been things that we would have missed as first time parents. It is reassuring to know that all of the resources we need are only a phone call away and that we can discuss any concerns we have about Casey with Reesa. If she doesn't know how to help us she will put us in touch with someone who does or she will find the information for us.

Infant Development is a great program! We will be sad to leave the program when Casey reaches 3 but we will know that he will be heading in the right direction because of the help we have received.

Tanya Mesheski



"The great gift of family life is to be intimately acquainted with people you might never even introduce yourself to, had life not done it for you."

-Kendall Hailey

Hi, my name is Linda Bechtold and I have 2 children who have received Infant Development through the Minot Infant Development Program. Our older daughter, Katja, is now 7 yrs. old. She was born about 7 weeks early and had a rough start in life. Aside from lung issues, she was also severely delayed in gross motor and fine motor skills. My sister is a special ed. teacher in the Bottineau School District and told us about Infant Development. I contacted them when Katja was just a couple of months old and she was evaluated and put in the program under the care of Koletta Ficek and Laurie Walker was her case manager.

Over these 7 years we have come to know and love both of these ladies. I can't thank the program enough for all the did for Katja. We received such wonderful and early intervention! At 11 months old Katja sat up for the first time unassisted so imagine our surprise when with continual, intense and loving care from Koletta and the excellent parent education she gave us, Katja entered the first grade completely caught up with the other children both academically and physically! That early start, I am convinced, is what made that possible. I also would like to share that at about a year and a half old, Katja began to show some intense sensory issues in many areas. I probably would have just chalked it up to being a girl or being fussy or whatever. Koletta noticed that this was a potentially big problem and after consultation with Kelly Dravecky (spelling?), an Occupational Therapist, we began a program of brushing and joint "stimulation." Katja also wore a tight neoprene vest to stimulate her senses even further. I am also convinced that without this intervention, we might have a different girl today.

Our younger daughter Natasja is 3 years old. She has been in Infant Development since she also was a few months old as she was born with a soft palate cleft. Her biggest problem with the cleft palate was ear infections and that having these infections has delayed her speech due to inability to hear well. She missed a lot during her first 6 months before ear tubes were put in. When Natasja was enrolled in the ID program, I quickly asked if we could have Koletta again since we had worked so well together in the past. With Koletta, we learned other ways to help Natasja communicate. This valuable information and teaching saved Natasja a world of frustration. She is doing well now and her speech is beginning to develop, but she has a long way to go. Some other things about ID that are important to us...While we do have medical insurance and my husband is able to work long hours at his job so that I can be at home to care for our children, the Medicaid insurance that we also received through ID was a big help when Natasja needed her palate repair and, so far, 3 sets of ear tubes. There are so many unforeseen and added expenses that go along with special needs, that having that added insurance made our children's care much less stressful for us and as a result for our children as well. Thank you for the services ID is able to offer families in need!

One thing that could be changed in our state...Natasja's surgery to repair her cleft, we were told, is considered "cosmetic." As such, it is not covered by many insurance companies as I understand it. Before the surgery, Natasja has 3 or 4 bouts of pneumonia from inhaling food into her lungs due to the gaping hole in her throat. Doesn't that seem as silly to you as it does to me?

Thank you so much for listening, take care,
Sincerely,
Mrs. Linda Bechtold

Our family joined the chaotic world of having an infant who has disabilities in November 2005 with the birth of our second child. Nothing could have prepared us for this world consisting of endless doctor appointments and countless therapy sessions. Enter the staff of the Early Intervention (EI) program of BECEP. With their support we are carefully navigating our way through the trials that our dear fragile daughter, Keera, faces.

Born with multiple diagnoses including Down syndrome, Arthrogryposis, GERD, bilateral club feet, dislocated left hip, and feeding difficulties requiring a feeding tube, Keera's physical needs are many. She has had physical therapists, occupational therapists, and speech therapists from both our local hospital and the BECEP Early Intervention (EI) program. There is a difference. It is the difference between a hospital therapist saying, "My goals for your daughter are…" and the EI staff asking, "What are your goals for Keera?" It is the difference between a hospital therapist insisting that she lift our baby's hand to her face ten times even if it makes her cry and an EI therapist helping Keera lift a spoon to her mouth as many times as Keera is willing to do it. While the hospital therapists are physically aggressive, the EI staff is aggressive in a non-physical way: brainstorming ideas to help us to teach Keera to help herself; encouraging and helping us to learn and use sign language; borrowing us equipment to enhance her at-home therapy, everything from a special feeding spoon to a communication device to a large wooden stander; and teaching us how to do therapy with her on a daily basis (working out once or twice a week is not effective for a healthy adult, nor is it effective for a child with disabilities). EI is able to see the bigger picture of helping Keera acquire functional skills.

The professional, in-home services offered to our family by EI have been invaluable. It is with apprehension that we plan for Keera's graduation from the EI program when she turns three later this year: Who will brainstorm with us? How will we afford all the special equipment she needs to progress when it is no longer available for loan from EI? Or will she have to go without? Who will teach us to help Keera by showing us therapies to do? Early Intervention is a program that needs to be not only continued, but also expanded for those children with extraordinary needs. It is essential that North Dakota's children with disabilities continue to have this opportunity for personal growth and assistance toward a level of self-sufficiency.

Deborah and Kyle Hellman

My name is Tabatha Worful, and I am the mother of Cory, Kyle, and Nathan.
Nathan was in Early Intervention until he turned three.
He wasn't learning to talk like my other boys did, so I was getting concerned. We found out about Early Intervention through the preschool teacher at Cando Public School. She gave me the number to get in contact with Lake Region KIDS. They evaluated Nathan to see if he was behind, and found him eligible to get services.

It was nice to have the guidance and support to help me learn how to help Nathan begin to communicate verbally. Nathan said very few words when we began receiving services two years ago. Through our home visits, we learned how to have some structured play periods and sit down and do things together, which provided some great opportunities for communication.

It was great that the home visitors are able to work with kids and their family in the home. It is a familiar, comfortable setting for us, and helped me learn how to help my son. It was a challenge sometimes to get home from work and be ready for our home visits when Sandi showed up!

There was nothing more disappointing than discovering the program ended when Nathan turned 3. He made very good progress, but more time would have been good for him. It would be nice if services could continue until kids are ready to go to school.

Nathan now has a good vocabulary it's hard to believe he was ever behind! He still has some trouble with certain sounds, but it isn't from lack of practice! There is hardly a moment throughout the day when he isn't saying SOMETHING! Thanks LR KIDS & Sandi.

There are some who dislike the following story, we have applied it in this booklet to illustrate what a family goes through in those early stages of having your child diagnosed with a special health care need or disability. For those who have not experienced these issues it is here to assist you in better understanding why services like Early Intervention are so vital to families.

WELCOME TO HOLLAND

by
Emily Perl Kingsley.

I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this.....

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills....and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away... because the loss of that dream is a very very significant loss.

But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.

Reflection

Do you ask??
Or turn away??
Do you really see me??
Or just turn away??
Am I really different than you??
Or am I a reflection of you??
Am I someone else's problem??
Or am I gift for everyone??
Do you feel sorry for me?
Or wish you would help??
Do you seek the strength to help??
Or do you turn away??
Do you see me as a burden??
Or do you see me as a blessing??
If God made you,
Did he not make me??
Are you big enough,
To put your world aside??
Then take the time
To see inside mine??

Will you share your best??
Then open yourself to see my best??
Will you make a difference today??
Or will you turn away??
How do you see yourself??
Do you wish to share??
Do you want someone to care??
Or just have them turn away??
If you searched your soul,
What would it say??
Give all that I can,
Or turn away??
Will you be one
To seize the day??
Or one of the many,
That turn away??

Rick Rask '06

North Dakota Early Intervention Data
Numbers of Infants and Toddlers Receiving Early Intervention Services, Fall 2005

	Number Served	Percentage Served
Birth to 1 year	129	1.72 %
1 year to 2 years	197	2.72 %
2 years to 3 years	285	4.00 %
Total served:		
(Birth through 2)	611	2.80 %

(NECTAC Part C Profiles, 9th Edition)

Numbers of Infants and Toddlers Receiving Early Intervention Services as of January 1, 2008 as reported in public testimony prepared by the Department of Human Services: 852 (Birth through 2 years of age)

Percentages served on 12-1-07 for the 8 counties which are home to human service centers are:

Williams (Williston)	4.49%
Ward (Minot)	2.09%
Ramsey (Devils Lake)	2.59%
Grand Forks (Grand Forks)	3.85%
Cass (Fargo)	2.96%
Stutsman (Jamestown)	5.39%
Burleigh (Bismarck)	5.09%
Stark (Dickinson)	6.20%

Number and Percentage of Infants and Toddlers Receiving Early Intervention Under IDEA, Part C by Race/Ethnicity, Fall 2005:

Race/Ethnicity	Numbers Served	Percentage of total # served
American Indian	93	13.46%
Black (not Hispanic)	12	1.74%
White (not Hispanic)	573	82.92%

Increase numbers served from 1995 to 2005: 265 children to 611

North Dakota primarily serves all infants and toddlers in settings that are natural to them and their families or other caregivers. In the fall of 2004, 96% of all children received services in their "natural environment" rather than a segregated or medical setting. (NECTAC Part C Profiles, 9th Edition)

In the reporting year of 2004-2005, 337 children exited Early Intervention services. 175 or 52% were eligible for special education services through Part B of the Individuals with Disabilities Education Act.
(NECTAC Part C Profiles, 9th Edition)

In testimony prepared by the North Dakota Department of Human Services on 1-9-08, the department reported that approximately 41% of children who receive Developmental Disabilities Case Management prior to age three continue to receive Developmental Disabilities Case Management after their third birthday.

2007 Survey information concluded that 85% to 88% of families receiving Early Intervention services in North Dakota reported:
Early Intervention has helped their family know and understand their rights.
Early Intervention has helped their family to effectively communicate their child's needs.
Early Intervention has helped their family to be able to help their child learn and grow.
(Jan.9,2008 testimony prepared by DHS)

Family Voices of North Dakota is a grassroots network of families and friends speaking on behalf of children with special health care needs.
www.fvnd.org or call 1(888)-522-9654

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