NWDSA
northwest down syndrome association

Create and nurture a loving and
inclusive community
celebrating every person with
Down syndrome.

March 11,2013

NWDSA works with over 1,400 families in Oregon and SW Washington who have a child with a significant disability. There is much discussion at the state level about education from birth and particularly kindergarten readiness. We are puzzled by the continuing erosion of services 0-5 in Oregon. As families stay connected to NWDSA through the lifespan we are able to get a clear picture of just how much services have been reduced over time. Contrast Eleanor Baileys experience in 1992 (see cover of book) with services now. Eleanor had three home visits a week from different specialist and a once a week parent support group where her parents met other families and she received more services in a group. Eleanor's family at age three were given three different choices of preschool options in their community, they chose an inclusive community preschool which was funded by Early Intervention. Specialist supported the staff at the preschool and transportation was provided.

Fast forward to 2012 we have parents receiving in birth to 3 as little as 1 hour visit a month. Multnomah has visits one hour a week with only one specialist; this is considered a high level in comparison to other programs. At age three some parents have no preschool placement for their child and have a home visit. A small minority are served in Head Start with minimal consult from specialists. Some parents are able to find inclusive preschools and get an average of 30 minutes consult to the staff. Finding these inclusive preschools is difficult and the expense is a barrier. Preschools are increasingly reluctant to accept our children as they don't have a good level of access to the skills and support needed from Early Intervention professionals.

Our children's civil and human rights and the dreams we all have for our children to be supported and belong are being ignored. We would like to see a real investment in this trusted resources and to trust the statements that are made at many policy levels that reference the needs of ALL children have our children's needs in mind also.

Does anyone sitting here today think that the needs of a child and a family with Down Syndrome can be met by one hour of service at the most once a week? We are experts on our lives and our families and know our history. Unfortunately, 8:30 in the morning in Salem presents a barrier to our ability to represent ourselves in person. We hope this letter and booklet will be considered seriously.

We are going to bring a group of families to the capital on March 28th 2013 but your budget consideration precedes this. We are happy to be a resource and give further information if you have any questions.

Thank you,

Angela Jarvis-Holland & NWDSA Board

www.nwdsa.org 503-238-0522

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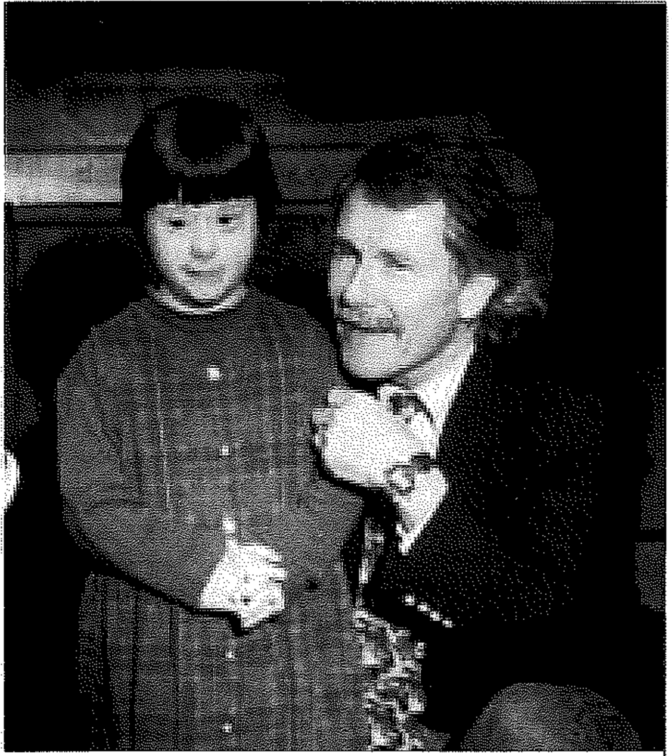
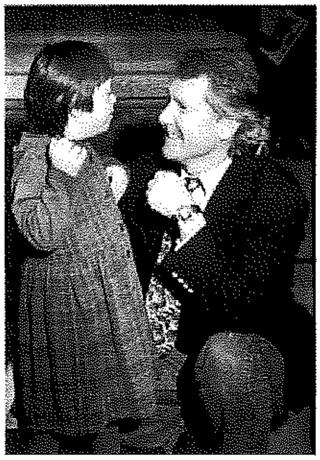
Early Childhood Special Education
Investing in Dignity and Capacity



Eleanor Bailey with Gov. Kitzhaber when the original Early Intervention Bill was signed into law in 1992.



In 1992, Governor Kitzhaber signed the Early Intervention bill into law. That law provides crucial services to thousands of children, including a young Eleanor Bailey. Those services put Eleanor on the path to graduation. In the last 6 years services have been cut by more than half. Don't take away an educational lifeline for our next generation of children.

Eleanor Bailey on her high school graduation day

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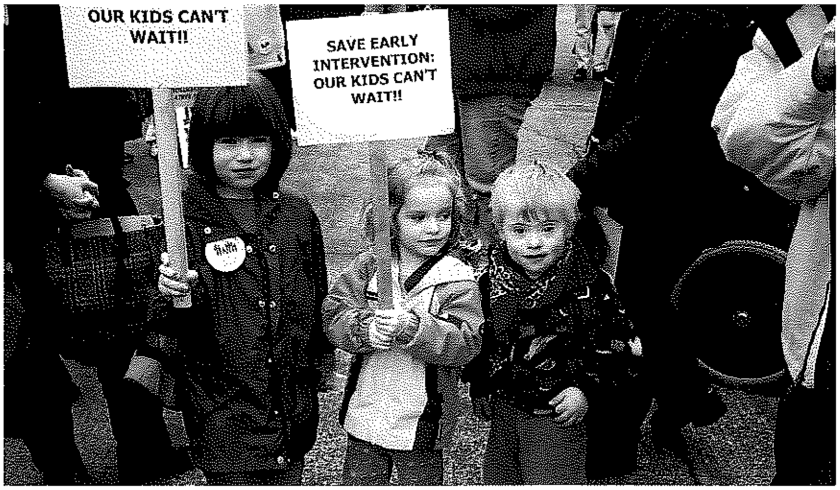
with Down syndrome.

The Northwest Down Syndrome Association is a parent-run organization that serves over 1,000 families and has been in existence for over 12 years. During that time we have witnessed the incredible progress our children can make. Research has proved the ability of the average person with Down syndrome to learn to read, write and earn a living. We have interventions that help with speech and learning and our kids face new horizons that were considered impossible just a generation ago.

This shift was supported by best practices-based Early Intervention. With the help of Early Intervention, parents learned new ways to help their children fulfill their potential, while at the same time becoming more empowered as parents. Many health insurance plans limit access to therapies for children with developmental delay and Early Intervention is the one universal free service available to all families. Professionals in the programs have deep skills and we need more access to the knowledge they can share. We as parents are willing to do our part and work hard to help our children. We are not, however, speech therapists, physical therapists, occupational therapists, or qualified teachers. Also many families are isolated and Early Intervention connects them with resources and groups such as ours. As with other investments in early childhood education, investment in our children while they are young better prepares them for school, in many cases saving resources in the long run.

We cannot go back in time and treat families in our communities as if their children cannot learn; we now know better. Our history as a local group has given us a clear picture of the impact of cuts, and we can see that we are on a knife's edge already with the viability of the current level of services. Far too many years we have had to gather parents and children together to protest cuts, only to see further erosion of supports. As parents and advocates, we know what works, we know we need support, but our voice is not very loud and our advocacy unfunded.

Eleanor (featured on the cover) was a small child when Governor Kitzhaber signed Early Intervention into law in 1992. She graduated from Grant High School in Portland with a regular diploma two years ago, and she now works with us and in the community doing presentations and advocacy. We need this effective investment in our community, we need to honor the dignity and capacity of all of Oregon's children and keep funding Early Intervention and Early Childhood Special Education. Every day new babies are born, every day infants are diagnosed with a need that Early Intervention is qualified to meet. We cannot turn our back on the next generation. This was signed into law for good reason and has proven itself to be a powerful resource for progress for our entire community.



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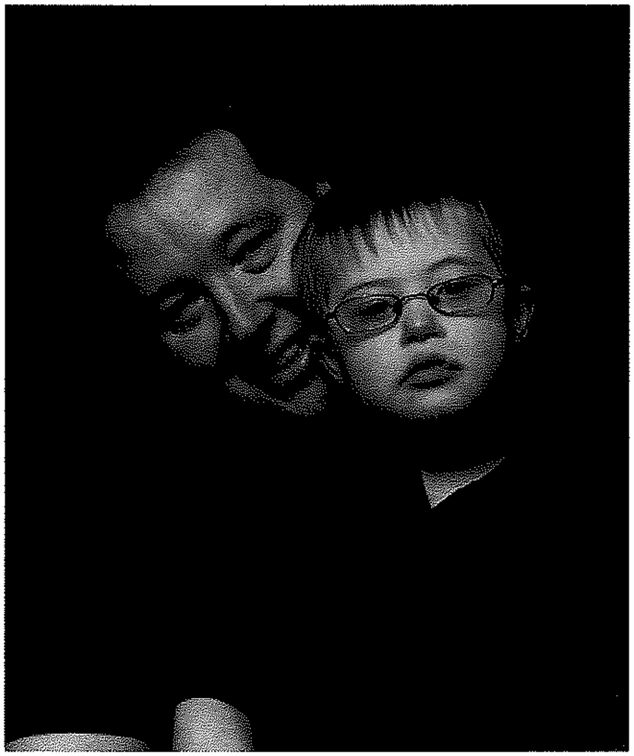
Sure, I go to sch
Same as you
I'm an Ameri



- Our daughter Mia Grace was diagnosed with Down syndrome at birth. We were first-time parents and had no idea, so there was so much to process and learn. **Early Intervention services began right away at 6 weeks old** and have helped to guide and equip us in a journey that felt so scary and unknown at the beginning. They have been with us all along the way and we couldn't imagine what that would have been like without people who understand so much more about developmental disabilities than we did to come alongside us and give us the tools, information and therapy Mia needs to thrive.

- Mia began receiving early intervention at 6 weeks old. **She receives Occupational Therapy two times a month through EI and vision services one time a month.**

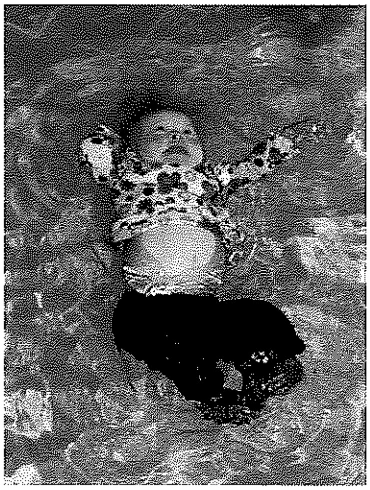
- *How many hours a week did s/he receive EI services?*
  One hour two times a month

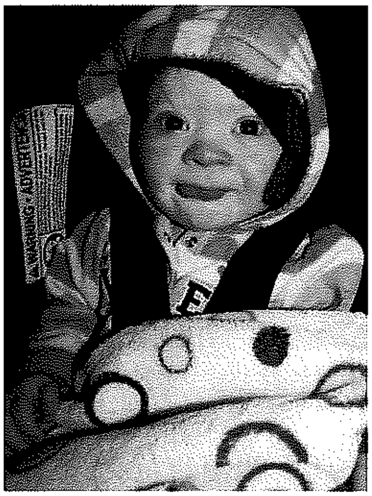
  She mainly sees an occupational therapist with occasional visits from speech therapy, physical therapy and vision services, all who have come to our home.

  The best thing about EI has been the direction and support it has given us. There is so much we are not professionals about related to development and how our daughter has different needs than typically-developing children. As first time parents, we would be lost about what to work on, what our goals should be and how to equip our child to thrive without help from our therapists. They have given us the knowledge, tools, activities and support we need to help Mia to grow strong and thrive.

- *Please share strengths of your child now, and one or two things they enjoy doing.*

  Mia is a social, playful and strong little girl. Her greatest strength right now is her success in her swim program. She has been in survival swim classes since she was 6 months old and she just earned her second blue ribbon for being able to fall in the water fully clothed, turn herself over and float for 5 minutes. I firmly believe that her being in these classes combined with the services she has received from Early Intervention have made her the strong, balanced and gregarious child that she is. Mia enjoys music and likes to help daddy play guitar and play her instruments.





- As a parent with a child with Down Syndrome, I now realize how important it is for me to understand the laws that apply to me and my daughter. However, the laws that are supposed to provide finacial and medical assistance have left us behind. We're currently on a waiting list for some of her medical needs, due to our State insurance a lot of services have denied my daughter. We're also in the process of applying for a scholarship at a Salem hospital for occupational therapy because our insurance denied her those services. She just started getting help through Willamette ESD, from what I've read some of those services are also getting cut. I would like to believe that our state legislatures that make these laws are human beings with compassion. Yet, they keep cutting programs that are supposed to be available for all special needs children.
- *What services did your child receive when s/he was an infant (age 0-3)* **-She has only received some from EI. Started at 4 months.**
- *How many hours a week did s/he receive EI services?* **One hour a month.**
- *Who provided services (i.e. teacher, early intervention specialist, physical, speech or occupational therapist) and where (i.e. home, center, etc)?* –Willamette ESDand at home.
- *What was the best thing about EI/ECSE for your family? How did your experience in EI empower you as a parent of a child with a disability? How did it affect your understanding of your child's potential and abilities?*- The best thing about EI for our family is that they show us the potential that our daughter can achieve with the help of EI .
- Vida has feeding issues, ASD(atrial septal defect), secundum, VSD(ventricular septal defect), hypotonia and dysphagia. With all of these complications Vida's strength is that she makes us not want to give up, even when some of our state laws have given up on her.

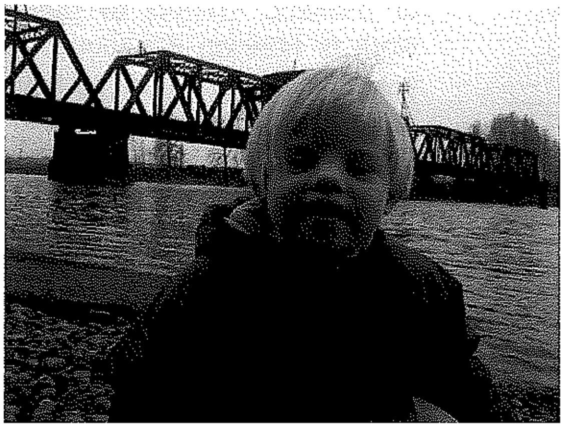
Vida enjoys playing with her favorite puppet named Juan Carlos☺

Adara just a few months old.

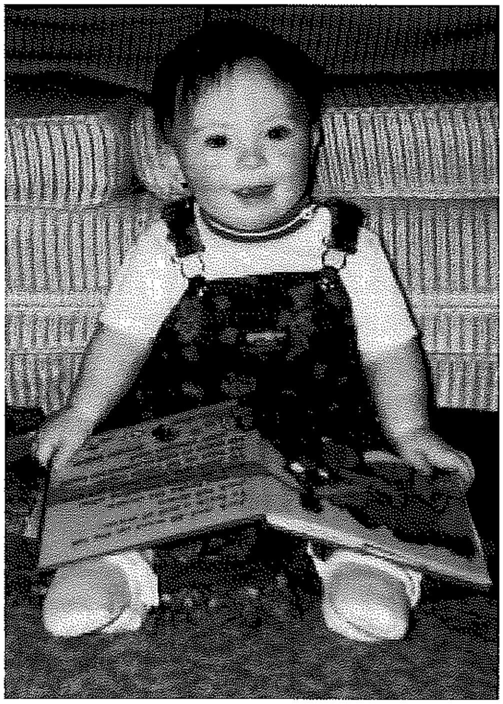
Our family began receiving Early Intervention services when Adara was 5 months old. For the duration of our time in Oregon, we received at minimum **one visit per week from a licensed physical therapist (PT) in our home.** The PT consulted with other team members as questions outside her area of expertise arose. Towards the end of our time in the program, **we also received visits from a speech therapist, but our total time seen was one hour per week.** These visits were personal, educational and vital to our foundation as Adara's parents.

For our family, Early Intervention was a very important part of our experience. **Having weekly visits from a therapist in our own home provided us with a level of insight and expertise to complement our work as parents.** The PT was adept at teaching us therapy strategies to incorporate into our daily routine with Adara. She taught us to use tools and toys around our own home, she considered us to be valuable "therapists" for Adara, and she empowered us to do the work we needed to do to support her needs.

Today Adara is almost 5, and getting ready to start kindergarten in the fall. She is a dynamic and social little girl who loves music, reading and playing outside. She is a kind and compassionate friend and big sister, and as we get ready to help her launch into public school, we are so grateful to have had the chance to build such a strong foundation for her to work from. MECP Early Intervention Services were a huge part of that positive start. Please preserve these vital services for future children. Everyone deserves a start like Adara's!



Adara today.



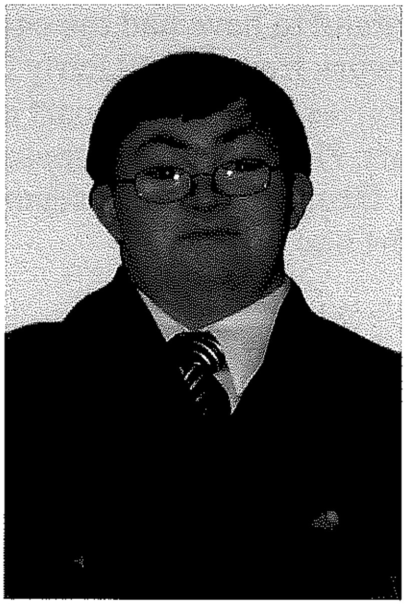
Early Intervention made a difference in our lives and in the life of our son, J.J. Ross. J.J., now 18 years old, is a junior at Trillium Charter School, fully integrated in high school classes, loving school and enjoying opportunities never dreamed of. It all started with Early Intervention.

At birth, we had no idea what to do. We were advised to contact Early Intervention. The first E. I. visit came when J.J. was 2 months old offering hope and possibilities. An E.I. specialist came weekly and gave us a variety of exercises to help J.J. strive towards developmental benchmarks. They shared information as to what was available which provided options. Toys, learning games, techniques, books and encouragement were part of each weekly visit. With the many advertised "must do" programs it would have been easy to spend thousands of dollars. Fortunately Early Intervention was there for our son and not there to 'make a buck.' Specialists not only worked with our son but provided information to help us discern what was best for J.J. and for our family.

At 3 years old, Early Intervention helped place J.J. in a preschool in the neighborhood and provided an aide to help support him in the classroom. JJ received speech twice monthly and physical therapy twice monthly. Our family was involved in a variety of Early Intervention services provided the first five years of J.J.'s life: group classes, parent classes, and individual support. All were beneficial and without a doubt gave J.J. firm scaffolding to build upon.

J.J. is an artist; he sells his art in the form of cards at bazaars. Thanks to the People's Biennial his work is now on a national tour. For the last five years he has enjoyed hip hop classes and recently has learned the joys of using his debit card when treating dates to movies and dinner. He has the potential of a bright future, of providing for himself and being a contributing member of society and doing what he loves.

We, his parents, know it all started with
Early Intervention.



We were told she might never walk.

Today, Julia is 5 years old and she walks... across balance beams, runs down the sidewalk, climbs the rock wall, catches a ball and hiphop dances. She is a bright, lovely girl who also happens to have a rare genetic disorder called Trisomy 9.

Julia received Early Intervention through Multnomah ESD from birth to three. The coordinated **care of our Physical, Occupational and Speech therapists** was invaluable to get Julia started on the right foot. She attended our **MECP Preschool class, and after 1.5 years, we felt confident she could function in a community preschool. Today, she attends Just Little People and receives MECP services there 2x/week with typical peers.**

We have had to rely on Early Child Special Ed services for Julia's development, especially in light of:

- Significant cuts to our insurance coverage for neurodevelopmental therapies
- New billing for services we receive at Shriners Hospital
- A lack of willingness of community preschools to accept kids like Julia due to lack of accessibility, experience with special needs or potty training requirements

Our goal is to foster Julia's independence toward a life as an independent, employable adult. We believe that...

CUTS TO EARLY INTERVENTION AND EARLY CHILD SPECIAL ED TODAY WILL COST OREGON MORE IN THE FUTURE in the form of:

- **More costly healthcare options:** MECP Physical Therapy has extended Julia's gross motor skills and likely minimized needs for surgery, other supports
- **More costly and less effective educational support:** Julia learns best in a general education setting with typical peers. Early child services help prepare her for that.
- **Greater dependence on services as an adult:** There is NO greater time than now to impact her language and motor skills to help build independence.

Sincerely –

Coleen Carey and Jim Honish, 3146 NE 16th Ave., Portland, OR 97212 503.287.6607

Daniel at his pre-school

Daniel was born 11 years ago and at the hospital they gave us a long list of all the things he could not do or would not do. It was a challenging time but in my arms was a lively and snuggly little baby that already seemed to be surpassing their expectations and showing a strong will to thrive.

At two months of age we had our first visit from Early Intervention. They chatted with me, held Daniel and began sharing some of the facts about Down syndrome. These included the fact that the average child with Down syndrome learns to read and write, the average child with Down syndrome will be able to work with some support in the community, and more good news. Much of what had been shared in the hospital proved to be wrong or outdated. **We then went on to have home visits three times a week, one hour in duration, with a physical therapist, a speech therapist and a teacher.** They encouraged, supported and taught us so much. I could relax and be a mother and take what they taught to use in our everyday activities. **We also went to a parent support group each week** where we could, with the help of a social worker, share hopes, dreams and fears and also laugh with others who understood our journey.

Later when Daniel was three years old, **Early Intervention gave us a number of choices for preschool.** I chose to pay for Daniel to go to a faith based preschool but I could have had him go to a free EI preschool. **We had a speech therapist, occupational therapist and teacher work with Daniel and the preschool to bring ideas, resources and activities that benefited** Daniel and many of the other kids also. Staff felt supported and learned a lot from the help of experts and Daniel thrived with some focus on the extra ways he needed help but also lots of learning from the busy preschool and fun typical peers.

Today Daniel is fully included at Sunnyside Environmental School in a typical fifth grade classroom. He is reading writing, using a computer and loves P.E. He is a true part of his school community and teaching many of his peers as well as continuing to learn a great deal. Just 25 years ago we were calling children like Daniel uneducable. We know better now. We know that children are lifelong learners, we know there are interventions and technologies that can support success. It is critical that we do not halt the progress of the next generation of children coming into Early Intervention who need a vision and support for their learning .Early Intervention has some incredibly skilled people working in it and we need to invest in the dignity and rights of all children.

Daniel, age 11, with his Brother Quinn, age 16:

- Andy is a young man in his 20s. He has autism, Down syndrome and celiac disease.
- *What services did your child receive when s/he was an infant (age 0-3)* **We enjoyed a home visit every week when Andy was a baby** where we could ask questions, the therapist could see us in our own home and help us with ideas to fit into our routines. We learned a lot about how to best help Andy grow and learn. **We also went once a week for 90 minutes to a parent group, therapists worked with Andy on his skills while we parents had snacks and a supported group to share celebrations and challenges with.**

- *What about for preschool (age 3-5)?*
  When he went to preschool it was for three hours a day five days a week and we could choose from two kinds of placements.
  We did some private therapy but this is very limited by most insurance plans and other parents did not qualify for any. I know that many families now receive far less support and needs that could be met are not always addressed.

Progress and knowledge is advancing but this will not continue unless we invest in early intervention.

My name is Jackie. My son's name is Ethan and he is four years old. **He is currently attending Early Intervention 3 days a week at North Powellhurst Elementary School**. Below are my thoughts about my experience with the Early Intervention programs:

What services did your child receive when s/he was an infant (age 0-3)?
None. I wish I had known about the Early Intervention program earlier, so that my son could benefit a lot more from this program and he wouldn't be so behind compared to his peers.

What about for preschool (age 3-5)?
Early Intervention.

How many hours a week did s/he receive EI services?
6.75 hours.

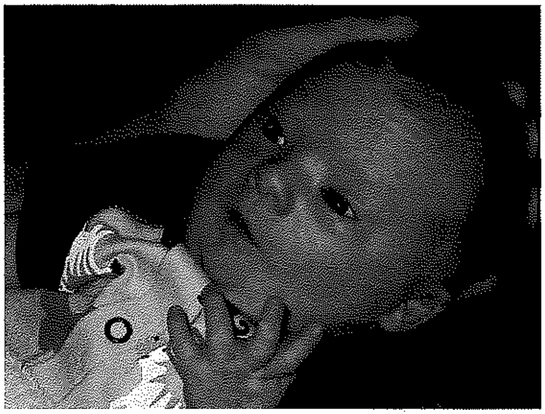
Who provided services (i.e. teacher, early intervention specialist, physical, speech or occupational therapist) and where (i.e. home, center, etc)?
Teacher, early intervention specialist, speech pathologist, occupational therapist. Most was done at school and some at home.

What was the best thing about EI/ECSE for your family? How did your experience in EI empower you as a parent of a child with a disability? How did it affect your understanding of your child's potential and abilities?
It teaches him to be independent, interact with other kids, self dress/undress, follow directions, communicate, use his hand to learn how to cut/color/write. I also learned a lot from this program to be able to help him with his daily communication, behavior, self dress/undress.

I really appreciate and love that my son is able to attend the Early Intervention program. He learns a lot. I always try my very best to bring him to school everyday. I don't want him to miss any day unless he is sick because I believe that he learns a lot everyday and everyday is important for him.

Please share the strengths of your child now, and one or two things they enjoy doing.
His communication is getting better. He is able to speak in sentences rather than single word/pointing. He loves singing some of the songs that he learned from school that make me feel very happy as a parent when I hear him sing.

Sincerely, Jackie



Parker Hulett
Born July 14th, 2009
Parents: Molly and Chris Hulett
Oregon City, OR

- Early Intervention has been such a blessing for our family. We were completely overwhelmed with all of our son's health issues, the diagnosis of Down syndrome, and all of the medical appointments that we had to go to the first few month he was born. When our team of people came into our home and worked within our routines it made my husband and I feel empowered and gave us direction.

- **My son currently receives 2 times a month home visits with Physical Therapist or education specialist and 1X month visit with a Speech Therapist. These services add up to 3 hours a month of service.**

- The best thing about our early intervention services is when we have been through some very stressful medical complication our team has really been there to support us through those tough times. Our IFSP says one visit a month for speech therapy but when our son had severe feeding issues our speech therapist was there for us and saw us weekly. Through her support we now understand the feeding needs our son has and are able to meet those needs.

- The sky is the limit for Parker. We know what we want in the future for our son and early intervention is helping us achieve these dreams.

- Our son is now 20 months old. He is the happiest child I have ever seen and loves to be around people. He loves to swim, chase his favorite dog Cosmo and loves to play with blocks, balls and cars.

- *What services did your child receive when s/he was an infant (age 0-3)*

My daughter received **physical therapy, later she started speech therapy and is currently continuing at her preschool and also is being seen by a special education teacher.**

- *What about for preschool (age 3-5)?*

She is currently receiving **speech and a special education teacher's services** at this time. She just turned 4 in February.

- *How many hours a week did s/he receive EI services?*
  She has been receiving on average about 2 hours of service a week.

- *Who provided services (i.e. teacher, early intervention specialist, physical, speech or occupational therapist) and where (i.e. home, center, etc)?* Her services started at home with an early intervention specialist, then a physical therapist and last a speech therapist at home. She started in a daycare/preschool at the age of 2 and her services for speech were moved to the school. They have continued her speech and she also is seen by a teacher at her daycare/preschool.

- *What was the best thing about EI/ECSE for your family?* One of the best things that came from EI is the fear that I had about not being able to help my child make it in this world was gone. They gave me strength and empowered me to be the best parent to my child that I can be. I had no skills, tools or even any concept of how to deal with or help my child with Down's syndrome. EI gave me the tools and the support that I needed to succeed as a parent and to help her succeed in life.
  How did your experience in EI empower you as a parent of a child with a disability? EI helped me to not look at the future with fear

but instead with hope and an understanding that Jasmine and I were not alone on this path we were on. I was able to look to the future and see the possibilities instead of the struggles. This came from the support that EI services provided.

How did it affect your understanding of your child's potential and abilities? I learned through EI that all things are possible. I came to an understanding that through the help of EI services Jasmine would be able to achieve anything. There would be work involved and it may take her longer. Having EI services to teach me and her as a team the struggle will be easier and together we can conquer anything that comes our way.

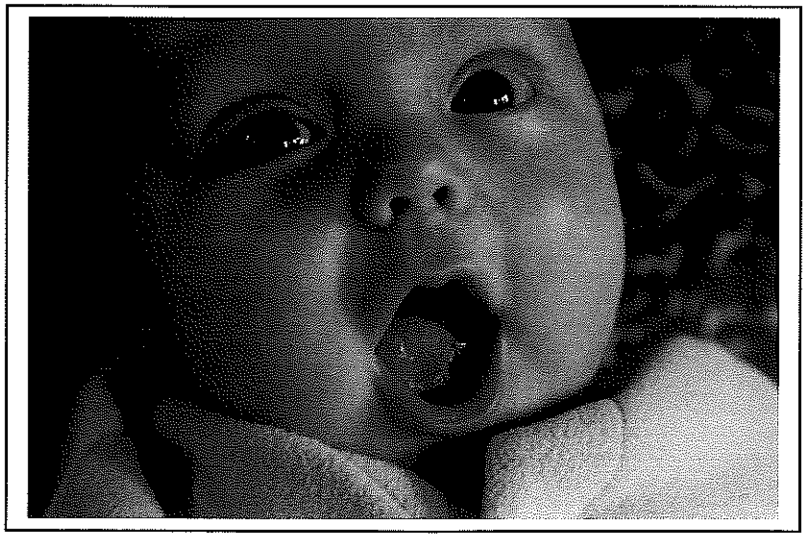
- *Please share strengths of your child now, and one or two things they enjoy doing.*

  Jasmine is a vibrant and happy 4 year old. She has just mastered 12-piece puzzles and will do them over and over. She loves to play with her friends at school. She is in a room with peers of her same age. She is in a group called the Anointed Angels at church and they dance to praise God. She is now beginning to communicate in sentences. I cannot always understand but she works hard with her speech therapist and is doing better every day. She has a great sense of humor and blesses people with her laughter all the time. She is one of the most empathetic people I know and will give a hug out freely to anyone in need. I cannot imagine where she would be without the help of early intervention. They are my strength and I consider them a part of the family that is here to help Jasmine succeed. She moves forward in leaps and bounds as we put our abilities together to help Jasmine be ALL that she can be. For me Early Intervention services are an answer to my prayers.

Adam on my shoulders

We carry our wounded out of the battle on our shoulders
We carry the next generation on our shoulders just as ours carried us.
We stand on the shoulders of the great so that the not yet great can stand on ours—Dragonfly Carlisle

My son rides through the market on my shoulders
The passers by smile at him mirroring
His love
His thatch of blonde hair tops a beaming smile so full of joy
Most people can't resist; I have never
Seen such love in the faces of
Strangers.
He squiggles to get down and I let him walk ahead
And he stops to pick up a pretty leaf, and seeing
A down and out homeless man, walks to him and
Presents him with his gift.
Beaming he walks on, the extra chromosome in each cell
Of his body seems to radiate light and love.
So unfortunate that they call this syndrome
Down's



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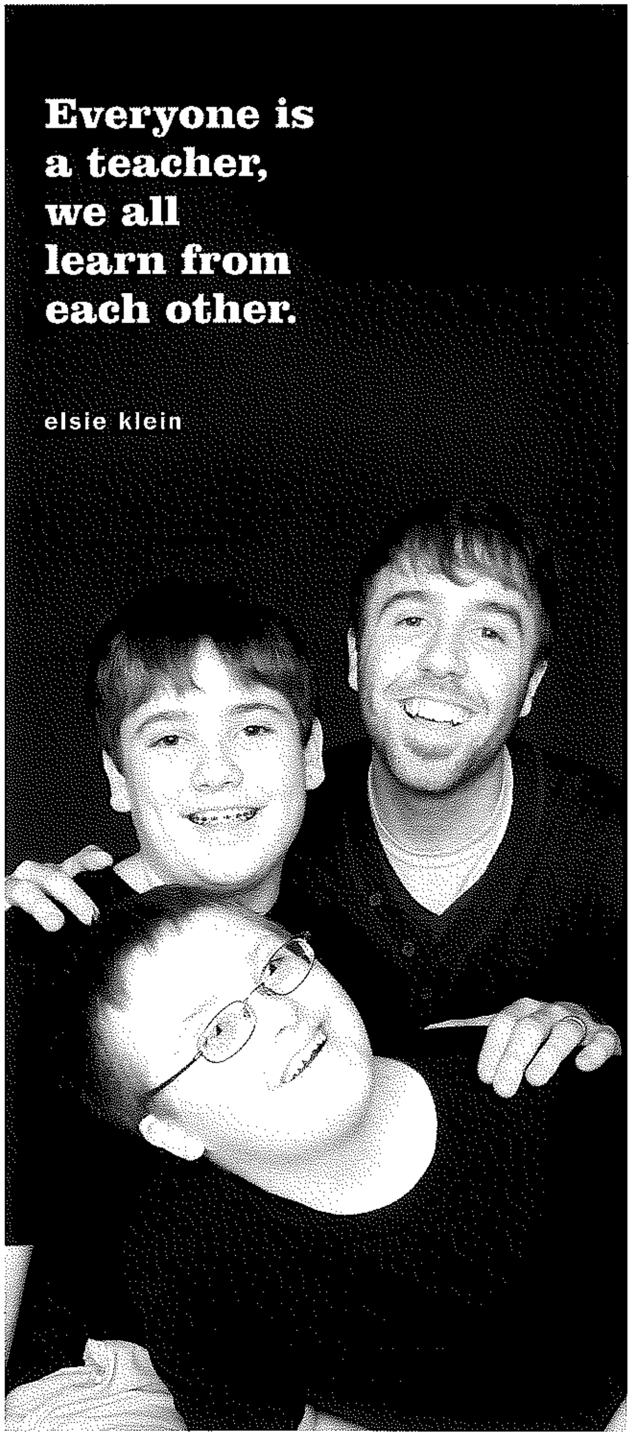
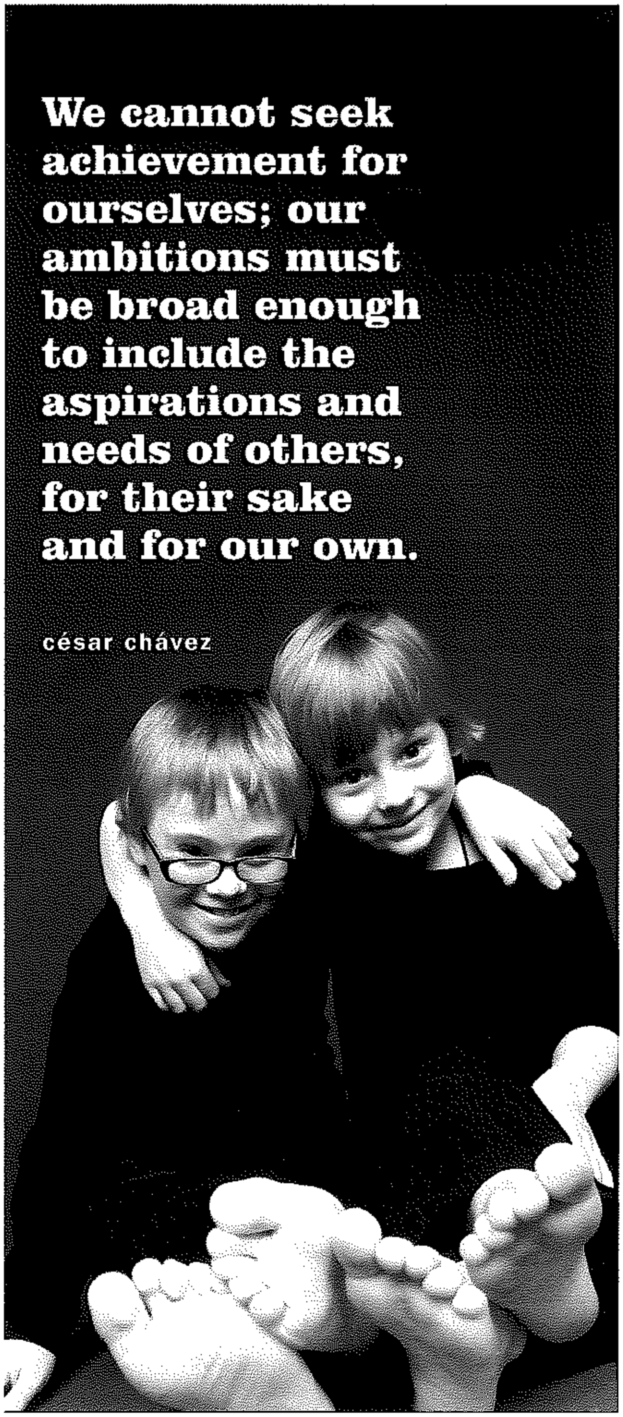


Everyone is a teacher, we all learn from each other.

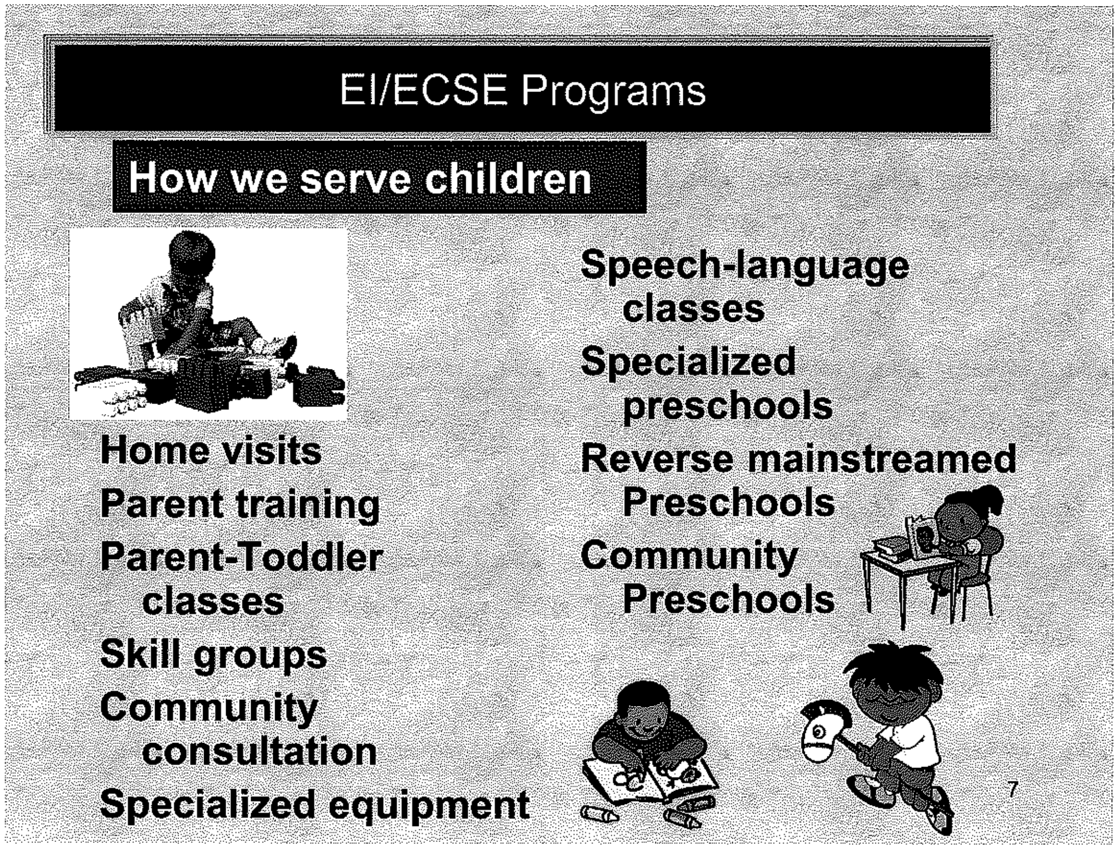
elsie klein

NWDSA mission: Create and nurture a loving and inclusive community celebrating every person with Down syndrome.



We cannot seek achievement for ourselves; our ambitions must be broad enough to include the aspirations and needs of others, for their sake and for our own.

césar chávez



EI/ECSE Programs

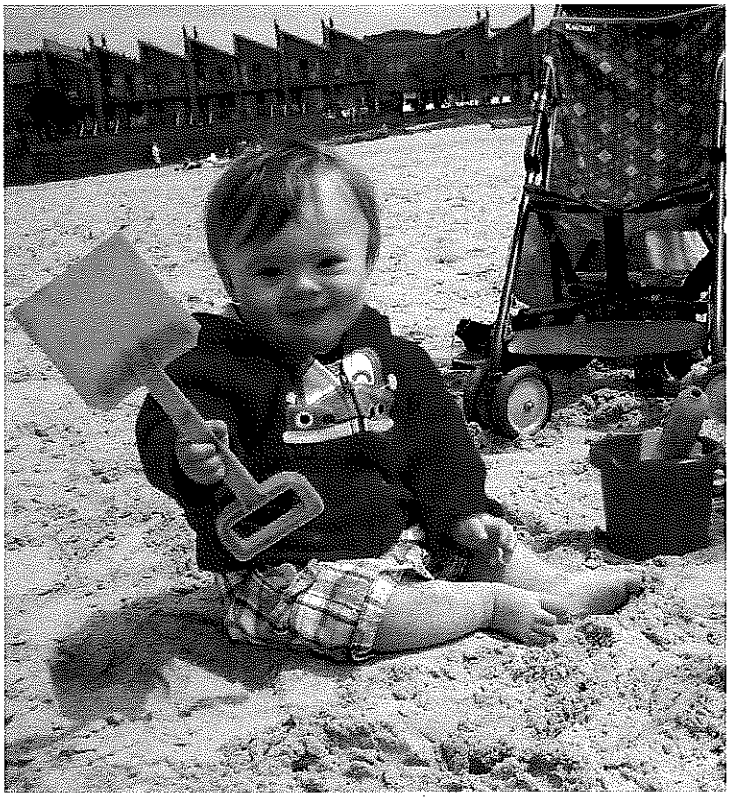
How we serve children

- Home visits
- Parent training
- Parent-Toddler classes
- Skill groups
- Community consultation
- Specialized equipment
- Speech-language classes
- Specialized preschools
- Reverse mainstreamed Preschools
- Community Preschools

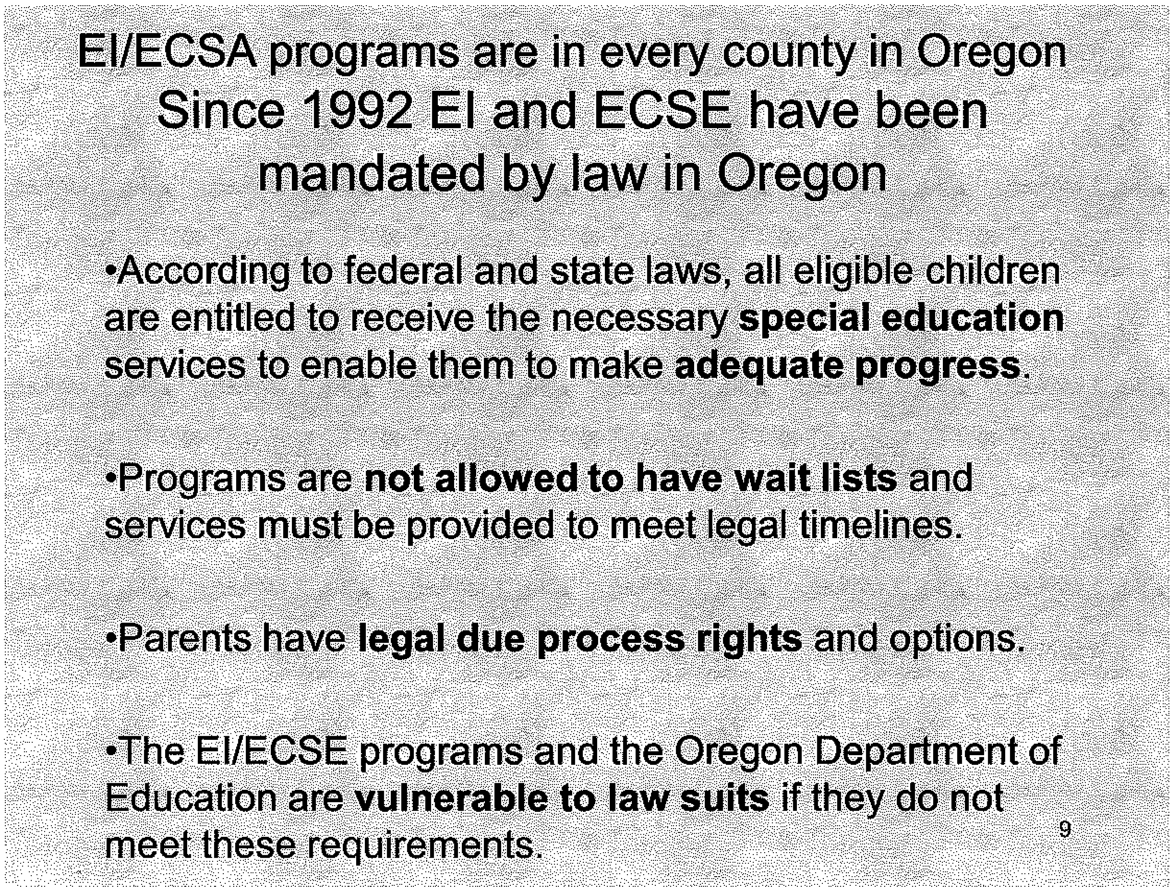
* PowerPoint slide courtesy of the State Interagency Coordinating Council

The EI/ECSE program utilizes "highly qualified" professionals

- Early Childhood Special Educators
- Early Interventionists
- Speech-Language Pathologists
- Occupational Therapists
- Physical Therapists
- Autism Specialists
- Behavior Specialists
- Deaf and Hard of Hearing Specialists
- Vision Specialists
- Interpreters
- Evaluators



* PowerPoint slide courtesy of the State Interagency Coordinating Council



EI/ECSA programs are in every county in Oregon

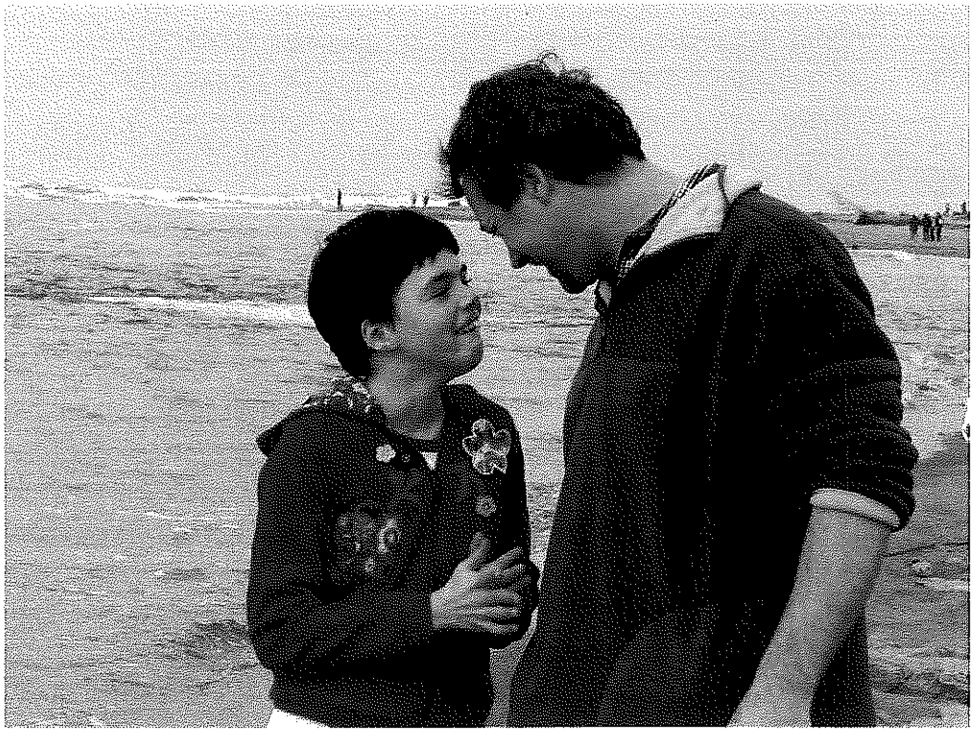
Since 1992 EI and ECSE have been mandated by law in Oregon

- According to federal and state laws, all eligible children are entitled to receive the necessary **special education** services to enable them to make **adequate progress**.

- Programs are **not allowed to have wait lists** and services must be provided to meet legal timelines.

- Parents have **legal due process rights** and options.

- The EI/ECSE programs and the Oregon Department of Education are **vulnerable to law suits** if they do not meet these requirements.



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