

oregon

PERSPECTIVES

A PUBLICATION OF THE
**OREGON COUNCIL ON
DEVELOPMENTAL
DISABILITIES**



Inclusive Education



OREGON
COUNCIL ON
DEVELOPMENTAL
DISABILITIES

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Send your submissions to the above address c/o Editor, Oregon Perspectives.

DEADLINE FOR THE NEXT ISSUE: October 15, 2007

ON THE COVER: *Zahra Detweiler (right) is a happy, social, seven year-old first-grader who carries herself with confidence and plenty of opinion of what she wants and how she wants it. Here she is with classmates Keely McCormick (left) and Caitlin D. Cochran (center) working on her schoolwork. (Photo courtesy of Linda Detweiler.)*

Correction: The first issue of Oregon Perspectives incorrectly identified the individuals featured on the cover. Our apologies to Kandi and James, pictured here, who both work for Port City Development.

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In many places, football is that thing - or maybe basketball, baseball, or another sport. That thing that makes everything else stop for just a little while; that thing that brings different people together with a common focus; that thing a community roots for, win or lose...

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Inclusion is Natural

In 1994, the Oregon Council on Developmental Disabilities hosted a debate on school inclusion. Inclusion was a hot topic then. Unfortunately, it still is in many parts of our state and nation.

Fast forward more than a dozen years and 3000 miles to Florida in 2007. When the Florida Developmental Disabilities Council hosted a conference on how to make inclusion work, they were criticized by people who wanted to debate whether or not inclusion is even a good idea.

Why, after so many years and so many successes to point to, is inclusive education still regarded by so many people as a radical social experiment? When attempts at inclusion fail, they can almost always be traced to a lack of resources and resolve to do it right – not to a flaw in the basic concept.

To understand the fundamental soundness of inclusion, all you have to do is think back a few years — in my case, about 50 — to those early days in school when you wanted nothing more from the school experience than to feel included — in the classroom, on the playground, at the bus stop, everywhere. And that desire to be included followed most of us out of the classroom and into our communities, our workplaces, our social lives. The same holds true for students with disabilities. School inclusion breaks down barriers and leads to community inclusion.

Instinctively, we all want to belong. We are social animals. It's in our natures. So let's stop talking about the "whether" of inclusion and focus on the "how."

This issue of Oregon Perspectives is filled with photos and stories about school inclusion — or lack thereof — from a variety of people who have known the struggles and rewards that come with trying to build school communities where everyone belongs.



Bill Lynch
Executive Director
Oregon Council on Developmental Disabilities

Inclusion is a Process —

Pushing for Inclusion at a System Level

The Family Action Coalition Team (FACT) and the Multnomah Parent Action Committee (MPAC) brought Kathie Snow to Oregon recently to share her perspectives on inclusive education and explain why parents need to be educated and remain resilient. Snow, a nationally prominent speaker and author, is also the parent of a college student who was included with his peers in his neighborhood schools.

According to Kathie Snow, inclusion can be defined simply: lessons are age-appropriate, in settings with a student's peers, in the neighborhood school, with an adapted curriculum. "Inclusion is a process, not an outcome," she says, "and inclusive education is messy. What's important is that

kids are in their neighborhood schools and known in their communities. They will grow up to be in the real world; they will not live in artificial environments, so how will their education prepare them?" She feels we should conduct a child's education with one question in mind, "Will this support this person to be independent, not helpless?"

Yet parents across the country and here in Oregon are fighting the same battles for inclusive education over and over. Snow noted that "while there may be good things happening in pockets, there is not a lot of systemic change occurring across the country. We need changes to teachers' curriculum across the country. We need to veer teachers, administrators, and some parents away from this presumption that our kids are somehow incompetent because they have a disability. Disability is natural. A child's disability should not define who she or he is."

To Snow, a spirit of teamwork and collaboration needs to be in a place within Individual Education Plan (IEP) teams. "Special education is not a place, it's services. In inclusive models that I've



Daniel Holland, far left, jamming with his band at Saturday market in Portland.

seen working, the special education teacher gives up his classroom and does co-teaching with regular teachers in regular classrooms. Specialists collaborate with teachers to provide services at appropriate times — like physical therapy done in the gym during the class P.E. time.”

Snow observed that teachers committed to inclusion value various ways of learning and provide flexibility based on students’ needs. Class divisions can be based on ability groups, focusing on what a child CAN do, rather than what she CAN’T do. Kids are good at helping kids, she says; teachers need to set up structures to facilitate peer support and provide modeling for students.

To parents, Snow says, “You educate staff and fellow students for your kid, you pick your battles and communicate, then you hope one more kid can follow you through the door you opened before it closes.” In order for the door to remain open for all students with disabilities systemic change needs to happen.



Niko Boskovic (center) at therapy session with classmate Roxie Louis (left) and Occupational Therapist, Megan Coate (right).

“...inclusion can be defined simply: lessons are age-appropriate, in settings with a student’s peers, in the neighborhood school, with an adapted curriculum.”

A Tale of Two School Systems

By Sharon Lewis

*I*nclusion means so many different things to different people. For our family, who recently moved from Oregon to the Washington DC area, working with the school systems to achieve a successful inclusive placement couldn't feel more different.

In Oregon, nearly every IEP meeting I attended was a struggle to maintain placement, to justify the good work of both general education and special education teachers, to plead for appropriate services and supports, to wrangle for an extra few minutes of therapy or a piece of needed assistive technology, to beg for help with curriculum modification, and to justify why inclusion in a general education classroom is the right place for the student. Good people struggle in resource-strapped systems; often the teachers and the students are left without the help they need.

The very existence of so many separate special classrooms influences staff and community attitudes towards inclusion of children with disabilities in negative ways. Often families are faced with the choice of watching their child be included in a general education classroom without the appropriate services, or being segregated into a class with only other students with disabilities in order to access supports, regardless of what is best for the student.

In our district in Virginia, inclusion is the norm. While there are resource rooms for small group and 1:1 work, there are no segregated classrooms serving as primary placement. Many general ed classes are team-taught, with both general and special education teachers

working together to support all of the students. Staff are staff; since no structural silos exist to separate and divide general and special education teachers, genuine collaboration and respectful attitudes are fostered. Most of the community sees the inclusion of students with disabilities as positive for all students, with and without disabilities.

IEP meetings are open, efficient, and constructive, with general education and special education staff clearly working together in positive relationships. Resources are available as needed; for example, our family was offered (without asking, begging or cajoling) significant increases in supports relative to my daughter's IEP from Oregon, without ever questioning her place in the general education classroom.

Even after-school programs and extracurricular activities are supported. The choices that families of children with disabilities face are the same as those of families of other students — band or chorus? Spanish or American Sign Language? drama or science club? — not whether the child will receive an appropriate education, have access to the general curriculum, or be able to attend school with his/her siblings, neighbors, and friends.

For our family, the comparison has been enlightening. Inclusion of children with disabilities in our schools in Oregon in real and meaningful ways is still the exception, not the rule. Despite our laws and our good intentions, attitudinal and systemic barriers still segregate and separate our kids. It is encouraging to know that it can look different, and that when inclusion is the expectation, it can be achieved without struggle.

Sharon Lewis is the mother of two daughters, one of whom experiences a developmental disability. Sharon has spent the last year in Washington, D.C. as a Fellow with the Joseph P. Kennedy Foundation, working on disability issues on Capitol Hill.

One District's Model

An Interview with Petrea Hagen-Gilden

Tigard-Tualatin School District (TTSD) is one example of a district-wide effort toward inclusive settings for all students. For 20 years, they have made the regular classroom the setting for all students, regardless of disability, then providing appropriate supports. Petrea Hagen-Gilden, Director of Student Services for TTSD, discusses the idea and practice of inclusive education in her district.

Oregon Perspectives: *How would you define inclusive education?*

Hagen-Gilden: The term inclusion used to carry so much baggage. In Tigard-Tualatin School District (TTSD), there was not a system of separate classrooms before, so it was not so difficult to take the services to where the children who needed them were. It is important that students be educated with their peers, in their neighborhoods, alongside the people they will share their community with in the future. A balance needs to be found between meeting an individual's needs and differentiating curriculum to include them. We aim to meet the needs of ALL students in our district, kids of all needs, regardless of their labels. In the core academics, we group students by instructional needs, so a student is not in a grouping based on a label but on what they need.

TTSD has a high rate of pullout time but also has a high rate of time spent in the general classroom. We have a lot of pullout because we do a lot of individualized programming that targets academic and functional needs for students. However, these students have a primary placement in a general education classroom. A more typical picture for students in other places is that if they need a lot of

individualized instruction, they are placed in a separate classroom.

We also do a lot of differentiated instruction for all kids, not just kids on IEPs. It is the norm for our reading and language arts program for students to receive instruction in small groups as needed and/or from teachers other than their homeroom teachers.

Oregon Perspectives: *How do you put inclusion to work at TTSD?*

Hagen-Gilden: Originally, my goals were to be better at providing the appropriate services for kids with disabilities, since graduation and achievement rates for kids with disabilities needed improving. Reading is a critical piece in the community so helping students find ways of understanding print in a way that's meaningful to them and the lives they want to have is a top priority. When I started, there was a lot of upheaval around autism; we needed to get a grip and position ourselves to serve students without setting up a separate system of classrooms. We needed to provide opportunities to learn in the environment students live in and to support their growing into their community. When a parent calls and says, "We're moving into your district... Do you have a classroom for kids with (insert label here)?" I respond that the student will be in a general classroom, and the team will figure out the best adaptive environment.

Oregon Perspectives: *What is working well for your district?*

Hagen-Gilden: The foundation of the success we have had is around the teaming. Parents, teachers, and specialists must work together for the best for the student. We embed what we do to address the student's particular needs into typical learning environments as much as possible. To do this, we must be creative.

Prioritization of services is based on kids' and families' quality of life and what they want in the long run. Setting up clear roles and expectations for various people in the teams is critical; problems come up when someone is unclear what they are responsible for versus what is another person's job.

In our district, we are fortunate to have an inclusively minded school board. Inclusion is the approved way, valued and supported. We have been good at recognizing needs and maintaining programs to meet those needs. The district has a commitment to instructional skills in ALL teachers, especially in Special Education. Active instruction is the focus, rather than case management or support, which is

Oregon Perspectives: *What have you learned?*

Hagen-Gilden: There is nothing a kid really needs to learn that cannot be taught in a regular setting. I have learned that if we think about things differently, we often can find a solution that makes sense. Families can be the very best inspiration and source of ideas on what we can do next. Work with families to figure out the best possible expectations for this child and be willing to change your way of thinking if you need to. All kids are capable of an amazing amount of incidental learning. This is critical for their future lives in their communities.

“The district has a commitment to instructional skills in ALL teachers, especially in Special Education.”

part of the package. Decisions on programs for students are based on data and on outcomes we see. We measure data, and we refer to it. Finally, the active Peer Tutoring at Tigard High School has been effective for students.

Oregon Perspectives: *What are the challenges?*

Hagen-Gilden: The most challenging thing we face is appropriately supporting children with intensive behavioral needs, regardless of whether or not they have a disability. Sometimes a plateau is reached for a time, then a student progresses again. We let teachers know that our data shows they are making a difference. It's important they know what they are doing has an impact. And money is always a challenge, especially as it affects the availability of space for team meetings or quiet space for students to go to.

Oregon Perspectives: *How will you build on your success?*

Hagen-Gilden: We are doing a lot with Response to Intervention (RTI). RTI is a way of organizing instruction to identify children needing academic help and to identify children who, even when they get extra help, make limited progress. We have been working with this approach since 2001. Since it became a requirement in IDEA 2004, we have become active in providing technical assistance to other school districts through Oregon Department of Education.

See related story on page 10.

An Oregon Pioneer

By Dennis Adams

Aaron was a pioneer, a leader. He went to high school in the mid-1990's. In those days, only a handful of students were full-time in inclusive settings and certainly none with support needs as significant as his. Aaron now takes things for granted, as most of us do, like knowing his neighbors and running into people he knows in his community.

In junior high, after many years with only occasional inclusive school activities, Aaron started full-time in regular classrooms with an aide. We found that having the aide took the responsibility for his education off of his classroom teacher. We also saw that Aaron's

classmates would interact more willingly with the aide than they did with Aaron. So when he moved on to high school, we pushed for him to be included full-time in the regular courses, with no aide. We were warned that if we chose the inclusive course there was no going back; there would be no special classroom to assist him if he had problems. Fortunately, we had a Director of Special Education who supported us as we made these decisions.

We valued public education and wanted Aaron to have the chance to have fun in high school and enjoy all of the activities. If he had his choice, he might stand still and not move at all – ever! Yet we encouraged him to move and to experience things, so he would be able to make better choices in the future. The regular educators made it work for us: the



Aaron and his sister, Alana, on the Truckee River.

Vice-Principal, the counselor, and the teachers made things happen for Aaron. The students who assisted Aaron to enjoy school all reported that the process was mutually beneficial. And when Aaron needed some expert, professional guidance to change behaviors that were not working for him — his fellow students provided it: “Knock it off, Aaron.” And he did.

Despite working with really good people, we were exhausted after junior high and high school. I have two children: my daughter is two years younger than Aaron. I’ve always said that both of my kids were perfect 51 percent of the time and normal 49 percent of the time. While my daughter does not experience disabilities and ended up being class Valedictorian, we realized after she

“We encouraged him to move and to experience things, so he would be able to make better choices in the future.”

graduated that it took as much time to support her through school as it did Aaron. It is not easy; it would be easier to let your kids slide, but we found ourselves constantly pushing the school staff to do more.

People have different values, different amounts of energy and time to offer. There is no one way to do things. Our values pushed our son to the

regular classroom and the opportunity to take part in all of the good things that high school had to offer. To make it work, we had to be pushy and friendly 100 percent of the time. Aaron graduated with his friends at age eighteen. He walked across the stage to

get his diploma to a standing ovation. Was it worthwhile? Yes, for both of our kids.

Dennis Adams is a Portland parent who continues to advocate for his adult children.

Perspectives from Tigard-Tualatin School District

Featuring: Karen Ripplinger, Sarah Anderson, Cleann Magone, and Sarah Eagles

Twenty years ago, the Tigard-Tualatin School District (TTSD) instigated a top-down change to an inclusion model, based on the belief that all children are equal. To gain further insight into how TTSD's model works, we talked with parents, teachers and professionals about their experiences there.

"Inclusion is much more than being included in lunch, recess and PE," quips Karen Ripplinger, whose son Alex is transitioning to high school. Sarah Eagles, a classroom teacher adds, "Inclusion means including all children in the same educational system. It allows kids to learn together and learn about each other at the same time. In our diverse world, it only makes sense to have all kids have the opportunity to be a part of the same classroom."

TTSD operates under the assumption that kids belong in their neighborhood schools, with supports to help them be successful. Cleann Magone, a Learning Specialist, says, "We provide education to students with special needs in the least restrictive environment. We start in the general education classroom and build a student's educational

program based on their individual academic and functional needs."

As an Educational Facilitator and an Autism Specialist, Sarah Anderson is able to see a big picture. She says, "Inclusive education put to work in TTSD is certainly not easy. It takes a lot of teamwork and dedication for all those involved. All staff need to be clear about their roles with a student and their responsibility to that student."

"The attitudes of the teachers and adults are the biggest factor in including kids with disabilities," says Ripplinger. "Since almost everyone in TTSD is used to inclusion, attitudes are accepting. Teachers and specialists work as a team. Kids receive what they need in terms of services/education and support. When professionals and teachers allow kids with disabilities to participate, these kids show that they can actually do it."



Alex Ripplinger (second from right) and a classmate use cooking skills learned in middle school while on a trip to Mexico.

Magone reveals her positive approach: "I love working with children, families, and professionals in an inclusive setting. I feel like I am part of a team that collaborates frequently about each student's needs." In TTSD, the Learning Specialist is a trained Special Education teacher who coordinates services as well. "I like the mix between being a teacher and being a case-manager. Most of my day is dedicated to teaching students reading, writing, and math. When I'm not teaching, I'm writing evaluation reports and Individual Education Programs. I call parents to check in with them and to arrange yearly meetings. I also check in with instructional assistants and teachers to problem-solve about concerns that come up related to the students I serve."

An inclusion model does have its challenges. "We can always use more assistant time and more time to communicate with the team," adds Eagles. "It is difficult to make sure the needs of all the kids are met and not being compromised by too much time given to kids with special needs. After the first few months, we usually develop a strong community of working together and understanding."

Parents and teachers seem to agree that inclusion is much easier in elementary school than in secondary schools. Ripplinger comments, "When Alex transitioned to middle school and during the years he has been there, I have had to advocate much more to get him into regular classes. At the beginning of every

"As a result of our inclusion model, children learn lessons that will last a lifetime: acceptance, understanding of diversity and the ability to interact and help others naturally."

Anderson works with teams to develop programs for kids who qualify for Special Education services and have low cognitive skills. "I am assigned to five elementary schools and one high school. I do all autism evaluations in my schools and develop programs for those kids to ensure they are progressing in their educational performance and goals. I work with school teams to include these students into their neighborhood schools, train staff on how to work with them, and write behavior plans appropriate for each student. I may work with the family to encourage consistency between the home and school for increased success in their overall skills." If staff have clear expectations as to what their roles are, things go much more smoothly for everyone.

year, I would have to re-do his schedule to include electives. One year, I had to advocate to get him into a home economics class that would be appropriate for him instead of having him clean the teachers' lounge to learn his functional skills." She worked with the team to get him into that class, where he learned social skills, reading recipes, and cooking.

As children grow, "the educational setting changes, goals change on a student's IEP, and the program changes accordingly," says Anderson. "The teams look for more opportunities like community outings and chances for students to practice skills in a natural setting, not only the school setting."

The structure of how middle and high schools are set up, with classes changing every 50 minutes, makes it more difficult to establish relationships, especially for kids with disabilities. Ripplinger comments, "In elementary school, one group of kids is always together as a class, making it so much easier to work on social skills and communication. The socialization with regular peers is different as kids get older.

believe he has learned to be more helpless due to this increased support. As Alex moves into high school, I know I will have to continue advocating for him to be included."

"The change to different classes and locations in middle school adds difficulty to the support system of the students," muses Eagles. "However, having grown up in the TTSD helps

"Children who learn together, learn to live together."

Alex was more independent in elementary school. In middle school, he has become more dependent on adults because he has had more adult assistants with him there. I

since so many kids already know each other." This gets at a critical piece: Children who learn together learn to live together.



Alex Ripplinger on stage (playing the body on the floor).

What is gained by this effort for an inclusive model of educating students? Eagles is strong in her response. "As a result of our inclusion model, children learn lessons that will last a lifetime: acceptance, understanding of diversity, and the ability to interact and help others naturally."

Ripplinger has advice for other parents, in any school district. "Try to create a balance, depending on what your child needs. Be realistic, and put your child into situations that

you believe they will benefit from and that they will like, like Alex and his Home Economics class. Be willing to try something out. Mostly, hang in there and continue to advocate in a positive and collaborative manner for your kids. Know the law on Least Restrictive Environment, and remember, inclusion is an ideology, not a law. "

Mediation and IDEA... Did you know?

The 2004 reauthorization of IDEA makes mediation services more accessible to parents and youth with disabilities so that conflicts can be resolved at an earlier stage in the process, rather than waiting until a complaint is filed with the Oregon Department of Education.

- ◇ Funding now comes from the Oregon Department of Education (ODE,) not from a school district, hopefully leading to a process that is less biased and more fair.
- ◇ The Oregon Department of Education draws from a pool of neutral mediators when a request for mediation is made by a parent or school district.
- ◇ If English is not a parent's primary language, the parent has a right to an interpreter in order to understand the IEP process and make informed educational decisions.

For more information on mediation and other dispute resolution topics, follow these steps:

1. Go to: Oregon Department of Education Web site: www.ode.state.or.us
2. Select: *Services*
3. Click on: *Dispute Resolution*

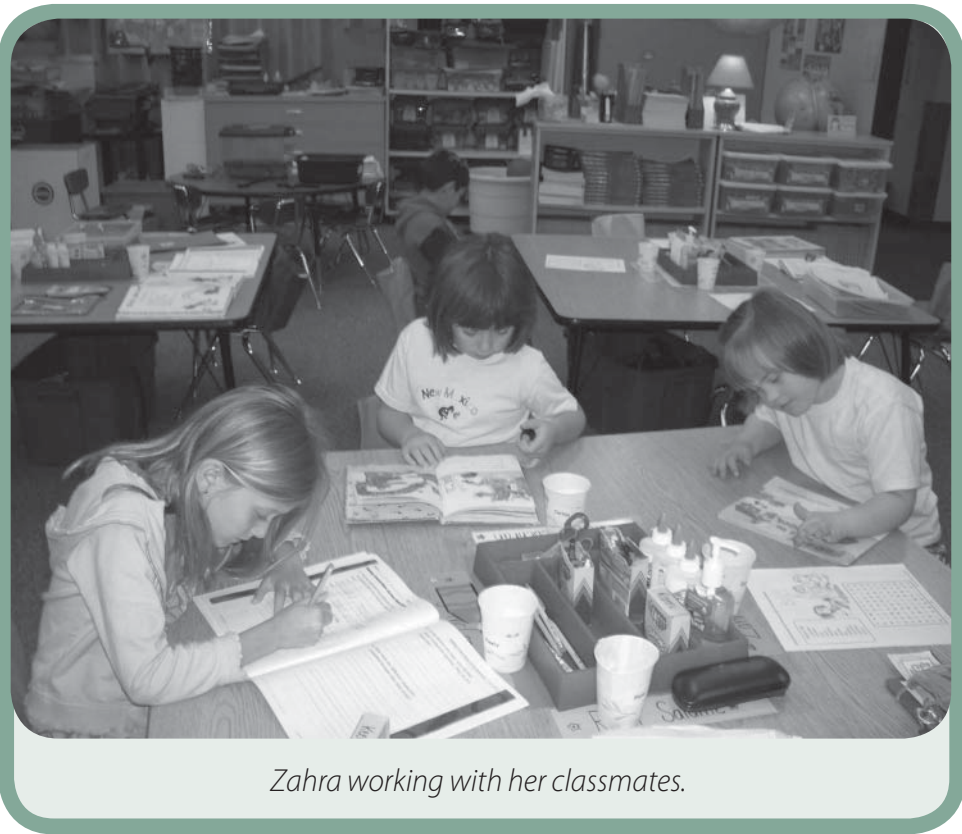
Just Like Other Students

By Linda Detweiler, Tualatin

On her way in to school, fellow students and staff address her with hellos and high fives. Zahra walks the halls of the school no differently than anyone else. She knows she is welcome and belongs; it is her school and her community.

The inclusive model at my daughter's school allows her to be assigned to a classroom, the same as any other child. There, she puts her things away, makes her lunch choice, and begins working at her desk, just like her fellow first graders do. She needs some support for this to happen successfully. Perhaps she needs an adult to follow her through parts of her day; she might need some small bits of help from a fellow student acting as a model, guide, helper, or friend to make sure she does what she should be doing. I spend as much time at her school as I can, making sure this is truly happening by staying involved in the process.

Our experience at her Tigard-Tualatin School District elementary school has been one I expect any child would like to have. If Zahra needs help understanding what the class is doing, it isn't just her assistant or classroom teacher that steps in. If she hesitates getting started, an unprompted classmate might pick up the morning writing sheet and ask her



Zahra working with her classmates.

if she wants them to bring it to her. On the playground, another student may give her an encouraging reminder that if she comes in from recess right when the bell rings she can help earn the class a reward bonus. It isn't unusual for a fellow student to bring her jacket to her if she is having a hard time getting things packed up for the day. This often is all it takes to help get her back on routine with the rest of the class.

It isn't always easy. Zahra doesn't always want to do what she is supposed to do because the class work and schedule are sometimes harder for her physically, emotionally, mentally, or behaviorally than for most first graders. Staff step in to help determine what her needs are and find positive solutions. Through communication between the classroom teacher, the Learning Specialist, assistants, and parents, the work is analyzed, taking into account her ability and frustration level, and then is adapted for her. She is in the room with her classmates almost the entire day.

When they break into reading groups, she and another group leave the room and she works on reading, communication, language, and speech. She then comes back to join the class in what they are doing and remains there unassisted for some time. She goes to lunch, recess, and PE or music with her peers and an assistant, and then she has a period of time in the classroom without extra adult assistance, participating in classroom activities. Before the end-of-the-day routine begins, an assistant returns to the classroom to ensure she is able to follow directions and pack up her things to go home.

“Here and there, we are reminded that there are small adaptations we need to make. Down Syndrome is a part of her life, but it isn’t her life.”

Zahra is a happy, social, seven year-old first-grader who carries herself with much confidence and plenty of opinion of what she wants and how she wants it. She has overcome heart surgery and related medical issues. She is an equal member of our family, for whom we have always had the same high expectations that we have for our other children. Here and there, we are reminded that there are small adaptations we need to make. Down Syndrome is a part of her life, but it isn’t her life.

Linda Detweiler is a parent from Tualatin.



Karley Burch mingles with kids at the zoo.

Inclusion for All

By Melissa Williams,
Ontario School
District

Ontario School District is one of Oregon's districts receiving training on Response to Intervention (RTI). Oregon Department of Education will provide formal training to 26 more districts this year. RTI is a process of identifying kids who need support with learning. Melissa Williams, an elementary principal, has been a critical part of this district's leadership team. She says, "I think RTI is a more equitable system, as you start with assessment of all students, whether they have a disability or not. It is done school-wide; supports are assigned based on data which we are tracking. I think it is a positive program for all of our students." She adds, "You should see the walls of my office. I have numerous pocket charts, one per grade level, full of colorful cards representing all of our students."

Ontario has a few factors that are challenging for educators. Malheur County is the poorest in the state. Approximately 50 percent of students are Hispanic, so there is a high need of services



Melissa Williams is a principal in the district who has been a critical part of their leadership team.

come to school with little or no preparation for the learning tasks of kindergarten.

“RTI has given more regular education opportunities for all students. Not only are they receiving special education services, they are being grouped with other students with similar needs, regardless of whether they have disabilities.”

for English Language Learners (ELL.) People in the area are highly mobile; students move from school to school frequently; and many students

The goal of RTI is to identify students with learning needs early. "We started this in elementary schools," Williams says, "but now we are beginning to use it in middle schools

too." Ontario School District uses the DIBELS (Dynamic Indicators Basic Early Literacy Skills) screening tool for the initial screening of all students. For students needing interventions, educators set up supports to aid them in their learning.

Williams likes that RTI is very student-focused and says "The students' performance measures the health of our system." Frequent review of the data assessing students' progress requires improved communication between educators and parents, providing an avenue for communication. Also, in an area where people move around often, the district now has more information that can move with the student, making district services and student education more seamless."

"We are improving instruction in all areas. For kids with developmental disabilities, there is

increased instructional time on their own level," continues Williams. Since all kids are breaking out into pullout groups to fit their needs, these groups do not carry a stigma. "We have a couple of students with visible disabilities who had gone through school for four years without much reading proficiency, but after two years of intensive intervention, they are readers now."

Response from Special Education teachers is very positive. "RTI has given more regular education opportunities for all students," Williams reports. "Not only are they receiving special education services, but they are being grouped with other students with similar needs, regardless of disabilities. There is a greater sense of group ownership, of community."

Melissa Williams is an elementary school principal in Ontario, Oregon.



Chalaine Reger (left) and Nanu Patel (right) visit the aquarium in Newport with their class from Ontario High School.

Educating Neva

By Alicia Delashmutt, Portland

Years ago, walking the neighborhood with my family, we came upon a large community garden too tempting for this landscape designer to pass by. As we wheeled our 6-month old daughter through the garden, we began talking to a teacher from the attached Early Head Start program. This random 'walk in the park' led us into a program that was looking to fully include Neva with the supports she needed.

Neva grew into a child who is drawn to music, movement, and food. She is a John Prine fan, likes classical music and her Duck Ellington CD. People are drawn to her, though I'm not clear how since she does not have a reliable way to communicate her needs. She learned to crawl at four and a half years old, and I love that she can finally search us out.

Neva's Early Head Start and Head Start experiences have been positive and accepting. She has never been denied access; she was welcomed. We spent a lot of time educating her teachers about her strengths, everything she loved, and all the things she could do. We taught them about her seizures and asthma, as well as her toileting, mobility, and communication needs.

The staff's willingness to communicate was key. Rather than taking a 'wait and see' stance, we worked with the team to front-load her assistance and helped set her up for success. We helped to lessen fears by showing that we were available any time to work with her team. We maintained a good relationship with her teachers, who learned that I expect her to come home messy because it shows me she was involved in class. When I hear teachers say



Neva Sinick, daughter of Alicia Delashmutt and Gary Sinick.

with trepidation, "We have never had a child quite like this..." I reply, "Well, neither has her family. If I can be her mom, with teamwork, you can be her teacher. None of us have all the answers, but together, we can make a pretty good run at it."

Neva is moving into Portland Public School's Kindergarten program this fall. To ease this transition, we forged relationships with the transition team early, going to informational meetings a year in advance of when we needed it. I got to know the players, taking initiative to call them before they called me. Just like planning a wedding, I tried to do as much as possible beforehand, so that I didn't freak out on the big day.

The transition team observed Neva at school, at our house, and came to our IFSP meeting. A month before the IEP meeting was scheduled, we asked for a meeting with the team to explain the IEP process to us. We visited different school options in the Portland area, including our neighborhood school. Knowing that the IEP is a communication tool and that the student and family have a voice in it, we asked for a draft copy of the IEP to review before the IEP meeting. We edited and added to the sections on “Present Levels” and “Family

placed in a general education classroom at her neighborhood school. I am glad we learned about the transition and the IEP process ahead of time since it is easy to feel overwhelmed.

This transition team now knows Neva well, but we’ll need to do all of this again every year, being interactive and working with the school as part of a team. Generally, I prefer to assume competence in my daughter and the people who work with her. I am clear about my hopes and dreams for my child. I am aware of her

“I would love to fix the system ... but right now, I just want my child to be a part of her world. I just want my kid to have friends.”

Concerns”, reviewed the goals set up for next year, and created a “Mission Statement” for our family.

The IEP meeting went smoothly, and the team proved very thorough and thoughtful. They included the input that we had given them, making Neva’s IEP document more personal. For our support, we invited an advocate from IEP Partners to the meeting, who shared with us her perspectives on content, took notes, provided another set of eyes and ears, and helped give us confidence. Neva was represented at the meeting by a photograph in our center, so we could all be reminded why we were there. We talked about Neva’s strengths, and I shared examples of small things she had mastered in preschool .

Regarding placement, we stressed that we wanted Neva to be involved in her community and to be included in a general education classroom in her neighborhood school, surrounded by her peers. The team agreed and decided that this placement could work for her. With full-time support, Neva was

rights, but would rather not have to use them to threaten anyone. I would rather appeal on a personal level and on what is right for my child.

How do you get the education that your child will respond to as well as provide opportunities for them to build friendships? We all live with people in the real world; we all need to know how to be a part of our communities.

Being your child’s advocate takes persistence and time. I am fortunate to work part-time in my own business, so I have the flexibility that it takes. You are your child’s best advocate. You know your child best. Educate yourself so that you can help educate your child. Ask questions. Don’t wait for someone to call you and ask for your input; by then, it’s usually too late. I would love to fix the system and will probably be working on that the rest of my life, but right now, I just want my child to be a part of her world. I just want my kid to have friends.

Alicia Delashmutt is a parent and a landscape designer in Portland. She is a graduate of Partners in Policymaking.

Imagine This

By Sharon Lewis

In many places, football is that thing — or maybe basketball, baseball, or another sport. That thing that makes everything else stop for just a little while; that thing that brings different people together with a common focus; that thing a community roots for, win or lose.

In our funky little public charter school, that “thing” is Destination Imagination. DI is an after school program where kids take on challenges by focusing on teamwork, problem solving, and creative thinking. Since our school was founded five years ago, we have had competitive teams qualify for state and national tournaments nearly every year. It is a point of great pride and high involvement for much of our school community.

As a first grader, and again in second grade, my daughter Zoe was an enthusiastic member of a DI team with her peers. But as the teams started to organize during her third grade year, I was told that she would not be able to be on the 3-4-5 team with her friends because “other team members would experience unnecessary frustration and stress due to Zoe’s personality” and that she could not be a “productive contributor” to a team.

When I vehemently disagreed, I was told that I was not being fair to the other students and families involved in the program. The youngest children participate on an “exhibition” basis, and in third grade the teams become competitive — I was told that I needed to understand the difference. We were offered “accommodations” such as allowing Zoe to participate in some of the activities but not others, or putting Zoe on a K-1-2 team with younger children, or having



Zoe's Destination Imagination team celebrates their success.

our family pay a 1:1 aide to support her during practice (which already involved two adults with only six or seven children) but then having her sit out of the competition.

I said no. I was devastated.

We had worked for four years to build friends, to contribute and participate amidst the chaos of opening a new school, to volunteer, and to be just another family in this community. I thought these people understood. I thought we had found a place of tolerance and acceptance. I could not believe that someone I considered to be a friend would talk about my child in this way.

After a good cry, and a therapeutic venting of words not fit for public consumption, I was still not certain how we were going to address this issue. I fired off a letter and spoke to the director of the program. I was having little success in working toward a solution when another coach heard about the situation. The children on her team invited Zoe to join them. They offered Zoe a place with no aide needed, no constraints, no exclusions — she would be a full member of the team, like her peers.

Fast-forward ahead five months, dozens of hours of practice, weeks of preparation, lots of work. Tournament day came, and Zoe had a great time with her friends. She did a terrific job with her part in the performance. I enjoyed watching not only the formal competition, but also seeing the other kids helping her get her costume on, making sure she was in the right place at the right time, keeping her with the pack of kids, and all of them laughing together as friends. Joyful in these successes and tired after a long day, our family left the local tournament a bit early.

Not long after we arrived home, the phone rang. Upon answering, Zoe, joined in the excited screams coming through the line. Not

The team went on to the state tournament, where they captured another Spirit award for teamwork and enthusiasm.

School inclusion and community relationships are at the heart of our decisions related to Zoe's life. If she had not been included in classrooms with those kids since kindergarten, if we had thought that spending her afternoons in specialized therapy sessions should be the priority instead of DI practice, if the other coach had not known Zoe's gifts and talents, if we were not in a community of people who pride themselves on acceptance, diversity and tolerance, if we had listened to the naysayers... — the bright smile that I enjoyed as Zoe stood

“School inclusion and community relationships are at the heart of our decisions related to Zoe’s life.”

only had Zoe's team qualified for the state tournament, they had won first place in their category! They had also won the tournament-wide creativity and teamwork award, over dozens of teams, 3rd-12th grade. And, as we learned later, the team had used Zoe's idea to win the “instant challenge” — the portion of the program from which the other folks had specifically wanted to exclude Zoe due to her cognitive differences.

Zoe had arrived. She was not just included. She was not just participating. She was contributing. She was a member. She would be missed if she were not there.

beaming on the stage that day with her team, her friends — real friends — would not be mine to treasure, as it is now.

Sharon Lewis is the mother of two daughters, one of whom experiences a developmental disability. Sharon has spent the last year in Washington, D.C. as a Fellow with the Joseph P. Kennedy Foundation, working on disability issues on Capitol Hill.

A Story of a Diploma

By Kirsten Thompson

*A*s a teenager, my son, Eric was excited to go to school every day and to be involved in what happened there. He connected with the adults and peers who taught, mentored, and inspired him and he eventually graduated from high school with a standard diploma. Because of that standard diploma, Eric was ineligible for any further transition services due to a law that states that a Free and Appropriate Education (FAPE) had been satisfied.

Eric has made in all areas of development. The happier he was, the better he responded. We were reluctant to change a placement that was obviously working for him.

When Eric transitioned from middle school to high school, all placement options were considered. After reviewing his progress, the team unanimously agreed that Eric should attend his home high school, a familiar environment with supportive friends and family, where he could pursue the skills and interests he had developed. It was important for him to maintain the relationships that were so critical to his development. It made sense to keep the same continuity, structure, and environment that had enabled him to flourish.



Eric Thompson leads his cross-county team in mountain training.

Since the second grade, Eric's least restrictive environment (LRE) had been in an inclusive placement in his home school. He has had an unusually high interest in connecting with and being a part of his peer group. The natural result of having supportive friendships with kids from his neighborhood and church, along with receiving educational supports and accommodations, has been the great progress

He was happy. The other option available to him would have been to attend the only other high school in the district, the one with a "modified diploma program." Realizing that placement in an unfamiliar place with no natural supports would be counterproductive for Eric, the team decided his LRE was a placement in his home high school, with

supports and accommodations including an instructional assistant.

Because Eric's school made an effort to individualize his program and somewhat modified the requirements of the curriculum to accommodate his special needs, we assumed that he would earn a modified diploma there and continue to receive the special education transition services offered to students with disabilities through their 21st birthdays. That would not be the case. At an IEP meeting during his sophomore year, it was brought to my attention that the high school would not award a modified diploma to him or any other student. In other words, the district did not offer modified diplomas at that school, only at the other high school.

We shared our understanding that a district had to award a modified diploma if it were awarded at another school within the same district. Over time and meetings the Special Education Director told us that the only way Eric would get a modified diploma would be if he were to transfer to "the program" at the other school. What sense did that make? Eric was deeply embedded and successful in his high school choir and track and was welcomed into a service club that actually did more

service for him. He was invested in his classes and was making progress academically. He was living the typical high school student's experience. Isn't that what most parents want for their children? Why would anyone want to set him up for failure at an unfamiliar place with unfamiliar people halfway through high school? It is hard enough for typical kids to make that transition — it would have been disastrous for a student with autism like Eric.

That is where Eric fell through the cracks of the system. Eric's support needs were and are as significant as the needs of students attending the "modified program" at the other school. Yet, because of his placement in the least restrictive environment as required by IDEA, he was the most restricted of all by being denied the services he needed through age 21 to prepare him for adult life.

We did everything in our power to help Eric make progress at school – and that progress was rewarded with termination of the very services that were critical for his ongoing success.

Kirsten Thompson is the parent of a child with disabilities.

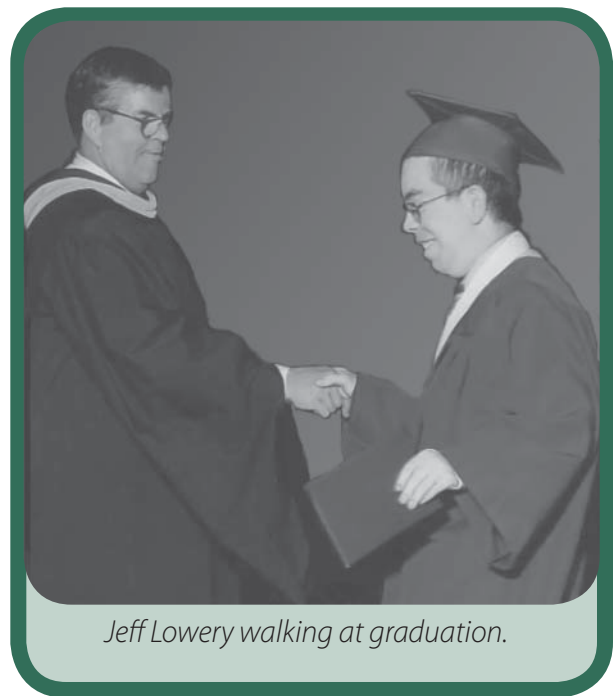
What is a Modified Diploma?

A modified diploma means there are significant modifications to the core curriculum for a student who is unable to meet the standard high school diploma requirements, even with reasonable modifications and accommodations.

Issues:

- ◇ Currently, not all districts in Oregon issue modified diplomas.
- ◇ Modified diploma means different things in different districts.
- ◇ Students who are in need of continued special education services until they are 21 cannot receive these services if they graduate with a regular diploma.
- ◇ Presently there is no guidance from ODE regarding modified diplomas and alternate certificates.
- ◇ Parents are not fully informed of the options and consequences of a modified diploma, alternate certificate, GED or regular diploma.
- ◇ Often students who don't get a regular diploma are not allowed to "walk with their class" during graduation.

House Representative Sara Gelser introduced HB 2848 at the request of the Oregon Advocacy Center. This bill creates opportunities for students with unique learning needs and disabilities to earn modified diplomas and alternative certificates when a standard diploma is not a reasonable option. This bill also guarantees that a student who has been awarded a modified diploma or alternate



certificate has the right to walk with the class at graduation. A modified diploma would not be called a special education diploma.

HB 2848 passed in the Oregon Legislature and was signed by the Governor. The law will take effect in 2008. A Modified Diploma Task Force of stakeholders and advocates from around the state has been created by ODE to study and give recommendations to the Oregon State Board of Education on how the new high school diploma requirements will affect students with disabilities. This task force also will make recommendations on the critical factors that need to be included in a modified diploma and alternate certificate.

Journey to Inclusion

By Marcie Ingledue

When our son Joey was two, we attended the National Down Syndrome Congress' annual conference in Anaheim, California. That conference changed our lives and gave us permission to dream big for our son. We left the conference with a new mission called "Inclusion" and a vision for Joey to become a productive, respected member of society.

While Joey received services through the Early Intervention/Early Childhood Special Education (EI/ECSE) program, we began to educate ourselves about the special education system and plan for Joey's transition into kindergarten.

Although we were apprehensive about what we might find in the public school system, we were delighted when Joey began kindergarten at his neighborhood school and was included in a regular education class with his peers. However, before starting first grade, we were told that Joey would be assigned to the Resource Room as a primary placement. The comment made to us was, "This is how we have always done it."

Needless to say, our knowledge about the Individuals with Disabilities Education Act (IDEA) paid off and Joey was fully included throughout his elementary school years. Never was it easy, but we were fortunate to have a wonderful extended family support system that allowed us to concentrate on an inclusive education for our son. This required constant advocacy to assure that he was a member of his class, not a visitor in the corner of the room with an educational assistant glued to his side. It required training for staff and constant

reiteration that inclusion benefits all children.

Joey continued to progress academically. Although all the kids were accepting and helpful to him and everyone knew him, we were worried that he didn't have "true" friendships. As Joey started fifth grade, we began to think about his transition to middle school. We put together a Person-Centered Plan, concentrating on the social aspects of his life, hoping that this would build some natural supports for him when he began middle school.

With approval from our principal and support from Joey's fifth grade teacher, we invited his class to a pizza party in their classroom after school. We sent a letter home to the families explaining the concepts of a Person-Centered Planning meeting and hoped we would have at least five kids out of the twenty-seven kids in the class. Well, food works; twenty-five kids showed up as well as some of their parents. We spent the next two hours discussing things that worked for Joey and things that didn't work for him. The kids knew just about as much as we did, and it was a learning experience for all of us.

Although the kids had learned more about Joey at the party, we didn't feel it would lead to any real changes. Boy, were we wrong. Within the next two weeks, kids started calling Joey at home to talk to him. The teacher reported that at recess the boys had invited Joey into basketball games. Instead of spending the entire recess playing on the slide alone, Joey was shooting hoops with the guys! His closest friends started spending the night on the weekends. By December, the kids encouraged Joey to sign up for Boys & Girls Club basketball. He loved it and played through his middle school years. He has been on a different team each year; however, the kids coordinate ways

to include Joey on the team and he has always played his share of minutes no matter what the score. In fact, Joey's team has won the league championship every year. In his eighth grade year, the team voted Joey the Most Valuable Player.

Although we had heard many horror stories about middle school, we were greatly surprised with the cooperation and support we received. The staff and administration supported our philosophy of inclusion, and Joey's transition was very successful. He attended general education classes and enjoyed supports from his peers and all the staff at his middle school.

The three years of middle school flew by, and though we were sad when we had to go through another transition, the 2006-07 school year has been exciting for Joey. He had joined band in the fifth grade and continued it through middle school, which gave him the opportunity to participate in the marching band at high school.

Attending Band Camp in August before school started was a great transition to high school. For two weeks Joey attended band camp from 9:00 a.m. to 9:00 p.m. He was welcomed by the kids who knew him from middle school and new kids transitioning from the other middle school in town. He worked hard, and when school began in September, Joey continued to attend evening practices in preparation for home football games and band competition in October. For six weeks beginning in October, we traveled every weekend to competitions throughout Oregon.

Joey has loved being a freshman. His future plans include finishing high school, going to college and then helping coach college basketball with his uncle someday. We all think this is quite ambitious, but it also confirms that our advocacy has put Joey on track to independence and self-determination.

Marcie Ingledue is currently the Executive Director of The Arc of Oregon. She lives in Grants Pass with her family, including children, D.J., Joey and Marissa.



Joey Ingledue marching with the Grants Pass High School Band.

In Joey's Words

I play in the pit for the Grants Pass High School marching band. The pit plays the big percussion instruments. I have played the bass drum, cymbals and an instrument that sounds like the ocean.

The best part of the band is the performances, when the audience is watching us. I love the music and the routine. Right before we go on field, the pit huddles together to say, "Do a good job." Once when I was sick, they waited for me before they did the huddle.

I feel like a part of the school because I'm with friends in the band. We work hard. I've even learned to beat box!

Joey Ingledue is a sophomore this year. GPHS finished third in the Northwest Marching Band Circuit Championships held in Hillsboro in November 2006.

Determined to be Included

By Jan Staehely

I remember my first experience in a regular classroom back in the early '80s. I was only supposed to stay for one period, but I followed the class to their music period. My teacher was searching for me because I was expected at my IEP meeting. When she found me I was happy as a bird singing with my class. She tried to make me feel guilty for being late to my IEP, but for once the guilt trip did not work! I felt like I was right where I belonged.

The IEP team and I decided I was ready to spread my wings at my neighborhood junior high, instead of going straight into high school. I was relieved because I did not want to be plunked down into such an intimidating environment straight off. I had two years to get used to my peers and how the system worked!

I was totally integrated into my neighborhood school except for two periods a day. Those two periods were dedicated to homework and getting a break from my wheelchair. I went to my new school not knowing anyone or having friends. When I got off the bus at home that first day, I broke into tears because I missed all my old familiar friends and teachers.

What worked to make me feel comfortable in my new school? I wrote an essay introducing myself to my new classmates.



Jan Staehely vacations on board a ship in the waters off Hawaii.

In the essay, I explained that I had cerebral palsy. I related my likes and dislikes, and how I expected to be treated by my peers. Then my sister read the essay on to a tape, so that it sounded like my voice, and the whole school listened to it. Shortly after that, I was making friends!

Maybe it was not such a good idea to let my peers play with my communication device, but it produced some more friends. Later on, I made sure my fellow classmates knew the communication device was not a toy!

What also helped tremendously was knowing my mom and dad were on my side, advocating for me. I won't forget my siblings in this picture because, without them, I would not be so richly blessed with personality!

Jan Staehely is a writer and advocate for people with developmental disabilities.

News and Views from the Oregon Council on Developmental Disabilities

Partners In Policymaking Applications Available Now!

Oregon Partners in Policymaking is an exciting and innovative leadership training program for adults with developmental disabilities and parents of children with developmental disabilities. Oregon Partners in Policymaking helps participants become better advocates for themselves, their family members, and the greater disability community. Participants learn about communicating and advocating effectively, services and supports, best practices and approaches, and current policy issues. They learn how to participate in the policymaking process at all levels, so that they can be equal partners in the decisions that impact their lives.

The Partners Program is only available to a selected number of participants every other year. Application forms were mailed out in September 2007. Applicants will be notified of their acceptance this fall and the Partners class will begin in March 2008. For more information check the Oregon Partners Web site at: www.oregonpartners.org.



DD Services Fare Well this 2007 Legislative Session

Unlike our more recent legislative sessions, economic conditions were good in 2007. As a result, the DD budget contained a number of significant funding increases including:

- ◇ Staley Settlement funding included an increased rate for Non-crisis Comprehensive 300, ability to backfill vacancies as they develop, and cost of living increases.
- ◇ \$20 million in General Fund was added for provider rates. In addition, providers received cost of living increases.
- ◇ \$1.4 million in General Fund was added to fund a new Medically Involved Children's waiver (HB 2406).

Fortunately, there were also a number of strong and committed allies in positions of legislative leadership in both parties.

For more information about specific legislation that passed this session, please go to the DD Coalition Web site at www.oregonddcoalition.org.

Photo left: A bill becomes a law — Family advocates gathered on July 12 for the Governor's signing of House Bill 2406. This law allows Oregon to seek a Medicaid waiver to provide in-home supports for children who might otherwise end up in nursing homes or foster care.

Celebrating our Community...and Taking Action



Developmental Disability Awareness Month was celebrated on March 12. Dr. Bruce Goldberg, Administrator of the Department of Human Services, read a proclamation from the Governor.



Representative Sara Gelsler (left) and advocate Sharon Lewis (right) received Developmental Disability Champion Awards.



The ceremony included the unveiling of a new awareness poster (above right) and a sculpture dedicated to everyone who lived at Fairview (left).



Photo above left: Rally Day at the Capital. Photo above right: Virgyna Hill (right) and Tony Newton (left) are Co-founders of the Victory Alliance Foundation.



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To receive this magazine in the mail, join the Oregon Network! The Oregon Network is a collaborative statewide network of disability organizations and their members, including people with disabilities, their families, friends, providers, and policymakers.

Members of the Oregon Network share information with one another, receive Oregon Perspectives and other publications, can learn about training events and empowerment opportunities, and have the chance to voice opinions on policy issues at the local, state and national levels.

Visit www.oregonnetwork.org to join today.

Upon request, this publication can be furnished in an alternate format for individuals with disabilities by contacting the Council.



*Joey and Jade Razzano
visit the capital.*

Oregon Perspectives

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