

# all born (in)



[www.nwdsa.org](http://www.nwdsa.org)

Cross-Disability Inclusion Conference  
April 18, 2009

Session Abstracts and Presenter's Bios

## Schedule for the Day

- 7:45 - 8:30 ..... Registration
- 8:30 - 8:45 ..... Welcome
- 8:45 - 9:45 ..... Keynote
- 9:45 - 10:00 ..... Break
- 10:00 - 11:10 ..... Session 1
- 11:10 - 11:20 ..... Break
- 11:20 - 12:30 ..... Session 2
- 12:30 - 12:45 ..... Lunch
- 12:45 - 1:30 ..... Keynote
- 1:30 - 1:40 ..... Break
- 1:40 - 2:50 ..... Session 3
- 2:50 - 3:00 ..... Break
- 3:00 - 4:10 ..... Session 4
- 4:10 - 4:25 ..... Refreshments
- 4:25 - 5:00 ..... Self-Advocates Panel
- 5:00 - 5:30 ..... Closing Remarks

## Morning Keynote

### The Importance of Belonging

David Pitonyak, PhD, [www.dimagine.com](http://www.dimagine.com)

Ambridge Rose Ballroom

*Belonging is critical to our well-being. Yet many people who experience disabilities are lonely. This keynote presentation examines the importance of positive, enduring, and freely chosen relationships. Participants can expect to develop a basic understanding of the importance of relationships as well as some specific ideas for helping someone they love to meet new people.*

## Afternoon Keynote

### The Dance of Partnership: Why do my feet hurt? Strengthening the Parent-Professional Partnership.

Janice Fialka, MSW, ACSW

Ambridge Rose Ballroom

*This keynote is designed to assist parents and professionals to better understand the challenges of forming working relationships. As a result of this presentation, participants gain insights about the partnership and are better able to collaborate effectively.*

*Using humor and stories, Janice explores the unique dimensions that complicate the working relationship between parents and professionals. She addresses such questions as: Can there truly be a partnership? What does each partner bring to this alliance? How can partners be more effective and compassionate in their communication?*

*Learning outcomes include: 1) A deeper understanding of both the parent and professionals perspectives. 2) A knowledge of what strategies promote the partnership. 3) A reframing of the concept of "in denial." 4) A renewed commitment to forming and sustaining partnerships. Janice draws examples from both her professional and parenting experiences to support her belief that the partnership is fundamentally important in creating strong supports for children and youth with disabilities.*

## Self Advocates Panel

### Our Lives, Our Voices!

Ambridge Rose Ballroom

*We make decisions about our own lives and direct where we are and where we are going. We have jobs, we have relationships, and we have meaningful lives in our communities!*

*We have all faced discrimination in our lives and faced challenges where others do not think we are capable. Well, that is wrong! We are more than capable of having jobs we enjoy, healthy relationships and friendships, a solid education, volunteer opportunities, and we have a lot of fun in our lives! We are individuals, and we are in charge of our own lives, just like anyone else.*

Andy Owens, Gayle Berniece Gardner, Susan Melero and Julie Sanchez make up the panel of Self-Advocates. Self Advocates As Leaders (SAAL) is a statewide organization of people with developmental disabilities interested in training and developing strong leaders to become equal partners in policy and legislation that affects our lives. We work for what is fair, gain independence, take control of our lives to fight discrimination, make decisions and choices that affect our lives, learn about rights and responsibilities, support each other, and speak out for what we believe in!

## Session # 1

### Supporting a Person with Difficult Behaviors/Supporting the People Who Care

David Pitonyak, PhD, [www.dimagine.com](http://www.dimagine.com)

Ambridge Rose Ballroom

*In David's view, what's most needed when a person engages in difficult behaviors is imagination. The story-line that is floating around about the person is a major part of the problem. What's needed is a new story. David's practice is based upon a simple idea: difficult behaviors result from unmet needs. In a sense, difficult behaviors are messages that can tell us important things about a person and the quality of his or her life. [www.dimagine.com](http://www.dimagine.com)*

David Pitonyak is interested in positive approaches to difficult behaviors. He believes that difficult behaviors are "messages" which can tell us important things about a person and his or her surroundings. Understanding the "meaning" of an individual's difficult behaviors is the first step in supporting the person (and the person's supporters) to change.

David has consulted with families and professionals throughout the United States, Canada, England, the Republic of Ireland, Northern Ireland, and the Netherlands. He lives in Blacksburg, Virginia with his wife Cyndi. They have two sons, Joe and Sam.

### Assistive Technology for Independence

Tom Keating, PhD and Director of Eugene Research Institute

St. Johns

*We'll discuss a range of technology that can help with people in supported living and the family members or others who are helping them. From useful gadgets to computer software to environmental sensors or handheld devices, there is an expanding universe of technology to help people of all ages manage the challenges of everyday life. Many of these are not expensive and are simple to use while others are more costly and complex. We'll review different products, demonstrate some software, including the Picture Planner personal organizer for individuals with cognitive disabilities, and look at "smart home" technology and its use in supported living. There will be time for hands-on exploration, and participants are encouraged to contribute their own technology insights and questions to the discussion.*

Keating is Institute Director at Eugene Research Institute, in Eugene, Oregon, which focuses on assistive technology research and development with an emphasis on cognitively accessible computing and design of systems for community living support, including creation of the *Picture Planner*™ icon-based personal organizer. He is also managing partner for Cognitopia Software, LLC, and is an Adjunct Research Associate in the Computer and Information Sciences Department of the University of Oregon. Keating's work over the past fifteen years has focused on the role of assistive technology in the lives of students and adults with cognitive and physical disabilities, on human interface design and development of cognitively accessible software for activities of daily living, and on intelligent systems for remote caregiving. His perspective in all of his work is strongly influenced by his role over the past 25 years as primary care provider for his brother James Keating, who has autism.

### Getting off to a great start: The power of parents

Roberta Dunn, Parent, FACT Coalition Director

Marquam

*Learning your child experiences disability is the beginning of a new journey, one we seldom feel prepared for. Roberta will share her perspectives, tips and tools for getting off to a great start. Areas covered will include perspectives on disability, developing a vision for your family, the importance of the parents' role and perspectives on what the future holds. This session is perfect for families with children school age and younger.*

Roberta Dunn is the mother of three teenage sons and lives in Beaverton, Oregon with her boys and husband of twenty two years. She has been a disability advocate since the birth of her twins fifteen years ago. One of the twins experiences Down syndrome. Roberta serves on the State Advisory Council on Special Education, is a Partners in Policymaking (PIP) graduate and is currently the PIP Program Director. She is also the Executive Director of the Family And Community Together (FACT), a group dedicated to empowering Oregon families experiencing disability by developing family leaders actively engaged in making sure that the perspective of families is heard and reflected in systems and policies that affect them.

## Session #2

### Assistive Technology for Pointers for Parents: How parents can take an active role in determining their child's needs for Assistive Technology

Gayl Bowser, M.S. Ed., [www.educationtechpoints.org](http://www.educationtechpoints.org)

St. Johns

*The Individuals with Disabilities Education Act (IDEA) includes a requirement that each IEP team must consider a child's need for Assistive Technology (AT). The requirement states simply, "In developing each child's IEP, the IEP Team shall consider whether the child requires assistive technology devices and services." How should your IEP team consider your child's need for assistive technology? How can you be a part of the decision making process? What is a parent's role in an assistive technology assessment? How can you participate in AT implementation and help your child to become more functional and independent.*

Gayl Bowser's work as an independent consultant focuses on the integration of technology into the educational programs of students with disabilities. Former Coordinator of the Oregon Technology Access Program (OTAP) and a special education teacher by training, Ms Bowser has also worked as a school administrator She works, regularly, with school districts to develop effective, legal and high quality assistive technology service designs. Ms Bowser provides assistive technology consultation, training and technical assistance throughout the United States and internationally.

Gayl Bowser is co-author with Penny Reed of five manuals regarding assistive technology for children with disabilities. They are:

- A School Administrator's Desktop Guide to Assistive Technology (2004)
- How Do You Know It? How Can You Show It?: Making Assistive Technology Decisions (2002 Also with Jane Korsten)
- Hey! Can I try that?: A Student Handbook for Choosing and Using Assistive Technology (2001)
- Assistive Technology Pointers for Parents (2000)
- Education Tech Points: A Framework for Assistive Technology Planning (1998)

"The most important contribution an educator can make to children with disabilities," she says, "is to believe in their potential and to insist on the very best each child has to offer." For this potential to be realized, children and the educators who serve them must have access to the best available information about assistive technology devices and services.

### Whole Life Transitions: Building toward a vision of inclusive life

Joe Wykowski, Executive Director of Community Vision, Inc., Melissa Halstead, Self-advocate & Joan Medlen, Parent, R.D., L.D. and Author

Marquam

*During the last twenty years Community Vision, Inc. located in has assisted individuals and families to gain control over their housing, employment and personal supports. Each person is supported to create a community life that is important to their unique interests and support needs while living one person at a time in communities of their choice. Transition to adult life should hold the same promises and possibilities for all people including young adults with disabilities. Included in the presentation are strategies to assist individuals with personal assistance, housing, community building.*

Joe Wykowski is the Executive Director of Community Vision in Portland Oregon, a person centered organization providing individual supports to over sixty individuals and families. Joe also founded the Homeownership Empowerment Program, which assists 15 individuals or families a year to purchase a home. He serves on the Multnomah County Housing Commission and the Mayor's Vision PDX planning committee. He is the Past President of the Oregon Homeownership Collaborative. Joe consults with various housing coalitions across the country concerning the creation of individual housing opportunities and personal supports for persons with disabilities. Joe is a guest lecturer for the

University of New Hampshire, Colorado State University, and University of Kansas. Joe was the recipient of the 2008 Walter Fuhrer Award for systems change.

### **Your vision, our tools: Getting services that meet your family's needs**

Jen Brandse, Parent, Coordinator of birth to 5 track for All Born "In", NWDSA Board Member & Ruth Falco PhD, Portland State University

#### **Morrison**

*For many parents, the first introduction to Early Intervention can be a whirlwind experience. Stay on your feet and learn about your rights and your responsibility as a parent. Find out who attends meetings, who you can invite, timelines, and tools to advocate for your child. Use what works in your family and the interests you want to share with your child to create your goals for your IFSP (Individual Family Service Plan).*

Jen Brandse has been on the board of the Northwest Down Syndrome Association since 2004. She is the chair of the Reciprocal Learning Community and has coordinated the birth to five track of the All Born "In" conference since its inception. She is a graduate of Partners in Policymaking class of 2004. In 2005 and 2006, she participated in SpecialQuest; the Hilton/Early Head Start training program. Jen is also the proud mom of Chloe, a 6 year old who has a flair for dramatics, can create more energy than nuclear fusion, and is finishing up her kindergarten year in the Hillsboro school district.

Ruth received her doctoral degree in special education from the University of Oregon. Her experience prior to her doctoral degree included serving as a teacher, consultant and administrator for programs serving young children with disabilities and their families. She is currently a professor at Portland State University. Ruth's teaching and research address issues in early intervention and early childhood special education. Her work includes development of curriculum and instructional strategies for young children with significant and multiple disabilities, including children with autism. In addition, she has directed two interdisciplinary personnel preparation projects focusing on collaboration with families to support inclusion and self-determination for children with disabilities. Ruth's current research focuses on interdisciplinary personnel preparation, collaboration with families, and early Braille literacy for children who are blind.

### **Creating an IEP with Inclusion in Mind**

Roberta Dunn, Parent, FACT Coalition Director

#### **Ambridge Rose Ballroom**

*Get comfortable with the IEP form from start to finish. Learn how to implement the education of your child through using the IEP as a tool. Learn the importance of the document and how to use it to secure an inclusive education.*

Roberta's bio is listed in session #1

## Session #3

### Through the Same Door: Inclusion includes college (a vision for all ages)

Janice Fialka, MSW, ACSW, [www.danceofpartnership.com](http://www.danceofpartnership.com)

#### Ambridge Rose Ballroom

*Janice will describe her 24 year old son, Micah's fully inclusive educational career from grade school, high school and now on a college campus in Michigan. In addition to showing the award winning film which documents his college experience, she will discuss the supports needed, the benefits and how to address the challenges encountered. Janice will also provide a brief overview of the national resources and trends in PSE for students with intellectual disabilities. See how it's done, learn how it works, and witness how Micah's journey challenges us all to reexamine what we believe possible.*

Janice is nationally recognized speaker and author on issues related to strengthening the parent-professional partnership, creating inclusive education, and opening post secondary education for people with intellectual disabilities. Janice speaks and writes from her unique vantage point of a mother of 24-year-old son with cognitive disabilities and as an experienced social worker of thirty years. She reflects with sensitivity, humor, and compassion on the challenges facing parents and professionals as they seek to build successful working relationships, especially in the work of creating fully inclusive communities. Her web site [www.danceofpartnership.com](http://www.danceofpartnership.com) is a highly regarded resource for parents, professionals, and advocates. Janice is also the Special Projects Trainer for Michigan's Part C of IDEA Training and T.A. In 2007, Janice was awarded the "Social Worker of the Year" by the National Association of Social Workers - Michigan chapter. In February 2009, Janice and her family received a "Life Time Achievement Award" from Family Voices for their work in the disability community.

### Early Childhood Transition: Parent's rights and responsibilities, rools to build a resume of inclusion

Ruth Falco PhD, Portland State University & Jen Brandse, Parent, Coordinator of birth to 5 track for All Born "In", NWDSA Board Member

#### Marquam

*What comes after early intervention services? At age three, children transition to ECSE (Early Childhood Special Education) and it's never too early to start advocating for inclusion. Find out about inclusive preschool settings and options when it comes to testing. We will demonstrate why it is vital to build relationships with the people on your child's team and the importance of parents staying in the driver's seat.*

Ruth's bio is listed in session #2

Jen's bio is listed in session #2

### Accessible Literacy for All

Shar Powell, Assistive Technology Resource Specialist/Trainer, Oregon Technology Access Program, [www.otap-oregon.com](http://www.otap-oregon.com)

#### Morrison

*Accessible literacy is for everyone. We can read a digital book from the computer, download it, put it on a CD or transfer it to an mp3 player and do homework while riding the bus home. So many options and so many books. Accessible Literacy is currently considered a "best practice" to provide access to instructional materials for students with disabilities, including learning disabilities. This class will look at the many ways to obtain accessible books and explore some of the alternative formats. Each participant will leave with an updated resource CD.*

Shar Powell, ATP is the Assistive Technology Resource Specialist for the Oregon Technology Access Program. Shar brings to the table 20+ years of diverse knowledge in several aspects associated with Assistive Technology; from building your own basic switch to the latest Augmentative Communication Device. Her abilities include, building, training and implementation whether in the classroom or one on one settings.

### **Beyond Bowling: A child's rights to thrive in inclusive and adaptive sports**

Steve Holland, President of NWDSA, Kenny Johnson, Director of youth basketball NE Community Center, Bonnie Doyle, Adaptive PE Instructor PPS & Isabella Curtis, High school student, Jessica Trent, Office Manager

#### **St. Johns**

*The panelists will provide a diverse and experienced perspective on the importance of physical activity for young people. A coach, parent, self advocate, and adaptive PE teacher will give parents, advocates, and professionals real life examples of what works for individuals with disabilities. Panelists will share what has worked for them, a reality check on expectations, and the individuals legal rights within the school and parks system. There will be specifics on resources, and recommendations on what they can do to maximize their children's participation in school, community, and after-school sports and physical activity programs.*

Bonnie has a Masters Degree in Elementary/Adaptive PE from Indiana University. She has taught adaptive PE for over 27 years for Portland Public Schools. Bonnie is a dedicated advocate for the rights of all children to participate in sports, and donates her services by evaluating teacher education programs throughout the country.

Kenny has a passion for youth sports, and has worked with youth of all backgrounds for over 30 years. He has coached youth basketball for more than 20 years. He believes in, and is an advocate for youth activities that "get kids moving." Mr. Johnson also worked for more than 13 years for Multnomah County Juvenile Detention. He currently directs the hugely successful co-ed youth basketball league at Northeast Community Center, and conducts after school gym for and basketball camps for school age children at NECC. Kenny is the founder and CEO of High School Prep Basketball, which is open to any high school age student who wants to learn the game, build self confidence, and become a positive member of their community.

Isabella is 11 years old and lives in NE Portland with her Mom & Dad, Jess & Daudi, as well as her 2 dogs June & Max, and 2 cats Fred & Fiona. Isabella is a 6<sup>th</sup> grader at Beaumont Middle school where she plays the drums in the school band. She enjoys swimming, acting, singing, science and telling jokes. Isabella has a condition called Arthrogryposis that has her unable to bend her arms and legs but does not let her stop her from doing anything!

Jessica is a manager for a local personnel development business that works with individuals and consults with businesses. Jess is Isabella's mom, and has been an advocate for Isabella for 11 years. She feels very strongly that all people should have the same opportunities for sports, exercise, and physical expression.

Steve is a graduate of the University of Oregon, and works as a Portfolio Manager for The Campbell Group. He is also the President of the Board of Directors for the Northwest Down Syndrome Association. He is the past President of the CFA Society of Portland, and a former Vice President of Southeast Portland Little League. He has two boys, Quinn and Daniel, and has enjoyed coaching both boys in baseball and basketball. He believes every child has a right to an inclusive sports experience, and that an active life leads to happiness and health!

## Session #4

### Instructional Design: Teachers and parents as partners

Paula Stanovich, Ph.D, Portland State University

Ambridge Rose Ballroom

*This session will focus on designing effective instruction through parent-teacher partnerships. Dr. Stanovich will provide an overview of instructional strategies that support the effective inclusion of students with disabilities in general education classroom settings. A universal access approach will be featured. Discussion will also focus on adopting a problem-solving approach when parents and teachers partner to provide differentiated instruction in an inclusive classroom.*

Paula is Professor of Special Education at Portland State University where she directs the Inclusive Elementary Educators Program. She has had extensive experience teaching students with significant and multiple disabilities, has conducted research into effective inclusive education, and has been an advocate of disability rights and inclusive education for over 35 years.

### Systems Change: Moving to inclusion with concrete examples

Dave Andrews, Supervisor MECP

Marquam

*This session will focus on preparing and moving an EI/ECSE program towards providing family driven and inclusive services. Strategies for culture change will be discussed along with specific examples of a family driven model for Early Intervention. Learn about the change process that is ongoing with MECP services for children ages birth-5 and about a specific Early Intervention strategy for family driven services (the Routines Based Interview).*

Dave Andrews has been a professional working with children and families in EI/ECSE for 15 years. He is now a supervisor with Multnomah Education Service District Early Childhood Program. Prior to supervising, Dave worked directly with children and families as a Speech-Language Pathologist.

### Kindergarten Transitions: Setting the stage for success, supporting the general education classroom

Ruth Falco, PhD, PSU & a parent panel

St. Johns

*Kindergarten transition can be a stressful time for parents. Learn how to decode the IEP (Individual Education Program) form. We will discuss eligibility, district guidelines, general education curriculum, school selection and goal writing. Look at concrete tools that parents can use to advocate for inclusive settings and hear real life experiences from a panel of parents who have been through this important transition.*

Ruth's bio is listed in session #2

Panel: Chloe Eudaly, Alicia Delashmutt, Steve Holland, Jen Brandse

### Session in Spanish: Asking the right questions and keeping your eye on the prize

TBA

Morrison

Northwest Down Syndrome Association presents

# **all born (in)**

a movement in pursuit of an inclusive civil society

**The following organizations, companies and individuals  
contributed generously to ensure this conference would take place**

Portland State University, Special Education

MECP

(Multnomah Early Childhood Program)

MESD

(Multnomah Education Service District)

Multnomah Developmental Disabilities Services

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The Standard Insurance

Patricia Wheeler

Martha & Rhidian Morgan

Community Vision

Disability Compass

DRO

(Disability Rights Oregon)

FACT—MPAC

(Multnomah Parent Action Committee)

& the generous contributions and in-kind  
support of numerous others

**For more information regarding **all born (in)** and how your  
organization can get involved, please contact the Northwest Down  
Syndrome Association at 503-238-0522**