

**April 2016** 

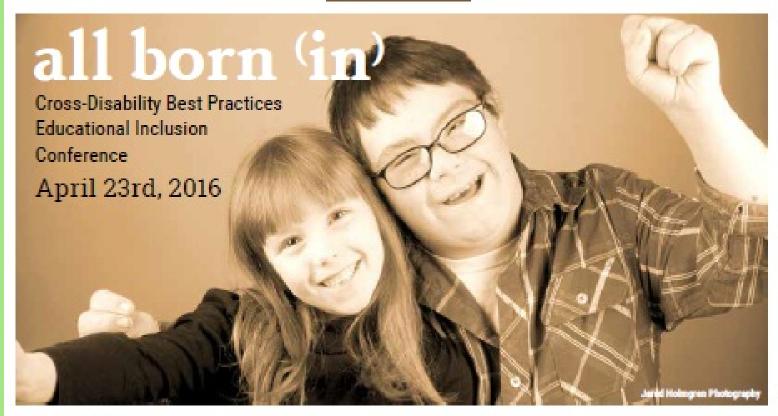
## **Spring is here - Find some outside fun!**



Check out some fun things you can do this Spring!

- Mud pies and mud soup are great for practicing cooking
- Create a race track out of bricks or rocks
- Build a nest out of sticks and grass
- Use pretend flowers, potting soil and shovels to plant some flowers
- Make paint out of chalk and water- make some cool footprints!

## Educational Inclusion Conference Opportunity



Tools, networking, and inspiration for parents, professionals, and community advocates committed to inclusion, Universal Design for Learning, and ending segregation.

### all born (in)

April 23rd, 2016 8:30 am - 5:30 pm, check-in at 7:45 am
Airport Holiday Inn • 8439 NE Columbia Boulevard • Portland, OR 97220
Register at www.nwdsa.org/allbornin • Registration fee: \$60 parents / \$80 professionals

11th Annual Educational Best Practices and Cross-Disability Inclusion Conference



Disability Rights Oregon wants YOUR input via its 2016 Community Insights Survey! Share what you think about the rights of individuals with disabilities.

This is an annual survey, which is one way that Disability Rights Oregon learns about the needs of Oregonians with disabilities. Your insights are important!

Click Here to fill out the survey!

# Success in Advocating for my daughter



Our daughter was born with a very rare genetic deletion called Cri du Chat Syndrome, She was diagnosed very early and was given a bleak prognosis by the geneticist. He warned us that she wouldn't have much of a life; probably never be able to walk or crawl or even roll over; that she would never learn to talk and may not even cry; and that she would most likely would just lie there.

Our sweet daughter has overcome so many obstacles to become the smart, active, expressive, loving, determined and brilliantly blue-eyed five year old that she is today. With the help of an amazing support system of family and friends, she has exceeded every expectation. She is crawling and standing with support, she is communicating through signs,

gestures, vocalizations and her speech generating device. The comprehension and knowledge are there, but she hasn't been given the right tools to be able to express what she knows.

In 2013, our daughter began specialized preschool. It was the first time she had the opportunity to go out into the community on her own. She even rode the bus at just three years old. We were so hopeful for the opportunities that the preschool was going to provide for her, but have found that our little girl was not receiving the supports and opportunities that she needed.

We started doing some research and became aware that the Oregon Department of Education (ODE) published guidelines that define "adequate service levels required to make gains" per age and developmental need. Our daughter falls in the "high need" category, and according to the ODE, that requires at least 15 hours per week with a 1:4 teacher to student ratio, a one time per week consultation and a once monthly family consultation or activity in order to make progress on goals.

Our daughter was receiving only 2.75 hours of specialized preschool twice per week. Her stamina was not being built up in preparation for full day Kindergarten next year, she was excluded from typical peers, and was showing minimal to no growth in many areas.

We also found out that we are not alone. The deficiency in service levels for young children with disabilities in this state is appalling, with only 1.4% of students in the ECSE "high need" category receiving adequate services in 2014.

We contacted our daughter's educational service district and relayed to them our expectation that our daughter's services be immediately brought to the standard level set forth by the Oregon Department of Education, and that these standard level services be continued through the summer before her transition to kindergarten. We asked that the district provide funding for her to attend a private preschool during the days and times that she was not attending her specialized preschool.

We are happy to report that with the help of advocacy leaders and mentors, and after many long discussions with the educational service district and an emergency IFSP meeting our daughter is now receiving the level of services she needs in order to make progress. We advocated for what she needed and finally she is getting the support she deserves.

Oregon Consortium of Family Networks

The Oregon Consortium of Family Networks is a formal partnership between family led community focused organizations around Oregon. Each organization is unique and is responsive to its own community and the strengths of the families who live there. Family Networks share the belief that peer support celebrates families as the tremendous resource they are. Sometimes the support we need is simply connection with someone else who shares common experience. Sometimes what we need most is another mom or dad, another sibling or grandparent, another neighbor or friend. That is the role of Family Networks - help connect families with each other, and help those families connect with their community.

#### Click the icon of the Family network working in your county to learn more about upcoming events close to you!



http://www.codsn.org Deschutes, Crook, and **Jefferson Counties** 



http://www.factoregon.org Clackamas, Multnomah, Washington, Hood River, Wasco, Columbia, Clatsop, Tillamook, and Lincoln

**County** 



http://www.roccosfamilynetwork.org Union, Baker, Grant, Wheeler, Malheur and **Harney County** 



http://www.featt.org

**Douglas County, OR** 



http://www.familiesfor http://www.creatingops.org community.org

Josephine and Jackson **Counties** 



Polk, Yamhill, and **Marion Counties** 



http://www.arclane.org/familiesconnected.html **Lane County** 





http://www.oregonaei.org

