
United Children & Parents

UCP's Quarterly Family Support Newsletter

United Cerebral Palsy Association of Oregon and SW Washington, Inc.

11731 NE Glenn Widning Drive, Portland OR 97220

503-777-4166

www.ucpaorwa.org

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Learning Opportunities for Your Child Through Alternate Assessments

Now I look at the possibilities instead of the limitations.

— Jeanette Forman, teacher

The U.S. Department of Education Office of Special Education recently created a 15 page report, which outlines the goals of the *No Child Left Behind Act* and *IDEA*. These “Big Ideas” include ALL children in the academic curriculum. Below are a few excerpts taken from the five “Big Ideas” in the report. At the end of this article are directions for how to obtain the entire report.

Introduction

No one cares more about your child’s welfare than you. No one else will be more careful to see that your child is well educated and well treated in school. Now there are efforts underway across the country to help you achieve those goals. The *No Child Left Behind Act of 2001 (NCLB)* and the *Individuals with Disabilities Education Act (IDEA)*; amended by Congress in 2004, represent some of the federal government’s largest investments in public education. Both laws have provisions that focus on improving the quality of teaching for all children, including children with disabilities, and both laws call for high expectations for the academic achievement of all our children.

Big Idea 1: High Expectations for All Students

The first big idea changing the way schools and parents plan is that all children benefit when schools have high expectations for what each student is expected to know and be able to do. Students with the most significant cognitive disabilities are participating in a curriculum based on the same academic content standards that all their grade-level peers are learning—content that is age-appropriate, engaging and challenging. Sometimes, they interact with this same content in slightly different ways from their classmates—through assistive technology, pictures, symbols or textures, or through whatever method they use to communicate. They also are showing what they have learned in creative and exciting ways.

Big Idea 2: Measuring Academic Achievement of All Students

One of the ways *NCLB* and *IDEA* work to ensure that the best education possible is provided to every student is by holding schools accountable for educational results. The tool to measure whether students have been well taught is called a state assessment. Results from state assessments help parents know whether schools have been successful in teaching students the knowledge and skills contained in the state’s academic content standards. That is why it is so important to include all students in statewide assessments—so that the public can hold schools accountable for all students’ learning. You and your child’s individualized education program (IEP) team will decide which assessment option is right for your child.

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Big Idea 3
Access to Grade-Level Content

Many children with the most significant cognitive disabilities have IEP goals that are focused on learning life skills. The third big idea contained in *NCLB* and *IDEA* recognizes that students with the most significant cognitive disabilities can learn both functional skills and academic skills at the same time. That is, we should not wait to teach a child to read until after they have mastered functional skills. As one researcher put it, “Students who are nondisabled are not expected to master cleaning their rooms or washing their hands before they receive instruction in reading.” Students with significant challenges can thrive by learning academic content while they are learning life skills, just as their typical peers do.

Big Idea 4
Making Decisions One Child at a Time

All students with disabilities must be included in statewide and districtwide assessments. The IEP team plays a role in deciding how a student with the most significant cognitive disabilities will take the statewide assessment. The decision should be based on educational needs and parents should be active in this decision process.

I found for our daughter that the topics of the 11th-grade curriculum, such as biodiversity and [the American novel], were engaging to her. They provided motivation that reduced the need for prompting.
— Mary Calie, parent

Big Idea 5
Counting All Students in School Achievement

Parents are often surprised when they find out that the statewide assessments used to measure the academic progress of all students are designed to give information about their own school’s progress in teaching their child and other groups of children.

The last big idea is counting all students in school achievement. It is important for students with the most significant cognitive disabilities to be included in statewide assessments and accountability. The scores of these students make a difference. These students count.

There was always a desire to include all students, but no one ever thought to use curriculum as a means to obtain full inclusion. Now, with inclusive accountability and a restructuring of the academic system in special education, children with the most significant cognitive impairments are contributing to the education system, and more importantly, they are learning.
— Daniel Wiener, educator

To order copies of the full report,

write to: ED Pubs, Education Publications Center, U.S. Department of Education, P.O. Box 1398, Jessup, MD 20794 1398; or **e-mail** your request to: edpubs@inet.ed.gov; or **call** in your request toll-free: 1-877-433-7827 (1-877-4 ED-PUBS). If 877 service is not yet available in your area, call 1-800-872-5327 (1-800-USA-LEARN). Those who use a telecommunications device for the deaf (TDD) or a teletypewriter (TTY), should call 1-877-576-7734; or **order online** at: www.ed.gov/pubs/edpubs.html.

This report is also available on the Department’s Web site at: www.ed.gov/about/offices/list/osers.

UCP Family Support Needs Your Help

We need your help.

From the early days of the UCP Family Support Program until mid-2006, the major portion of our funding was provided by The United Way. For the past year, we have been attempting to replace that with a stable, on-going source of financial support to keep our services intact.

We are seeking businesses and corporations that believe in the value of the work we do, and would be willing to sponsor our services on an annual basis. If you know of any businesses that you think would be interested in supporting our work, please let us know. If you have relationships with corporations or businesses, and could speak with them about the benefits you receive from UCP Family Support, that would be helpful as well.

The Walk 'n' Roll funds are given exclusively to the Family Support Department. This is our main fundraiser, but it does not yet generate enough funds to cover our annual budget. In 2007, the Walk 'n' Roll earned just over \$31,000. The Family Support Department budget for one year is just over \$91,000. We're hoping to find a number of sponsors that can help us for the next few years until we secure more stable funding (and as the Walk 'n' Roll grows).

We need your help and your best thinking. We're doing everything we can to find funding. As our main audience, we figured we would ask for your assistance.

We would appreciate hearing any ideas you may have, or referrals for contacts we can make.

Thank you!



Congratulations are in order!

United Cerebral Palsy's Supported Employment program has helped a handful of people with disabilities find employment this year. Though a Job Developer's work is challenging, kudos go out to each and every person with disabilities who find the courage to put themselves out there, and the commitment to persevere until they become employed.

Leslie Hobaugh was hired at Community Newspapers on March 2, 2007. He is a Tear Sheet Clerk – responsible for tearing out advertisements (from the Portland Tribune) and mailing them to businesses, as



proof that their ad ran. Leslie spent most of his adult life working in sheltered workshops – getting paid less than minimum wage, with no chance of bettering his situation. After being let go from a NIKE workshop, Leslie sought competitive employment and hired Melissa Miller at UCP to help him find a job. Leslie has an excellent memory for numbers, dates, addresses and phone numbers. Though he is deaf, he has developed ways of communicating with hearing people and coping in the hearing world. Leslie was hired during his interview at Community Newspapers because Mike O'Shaugnessy saw his potential. Leslie has been employed for 6 months now and he is very happy. He has his own cubicle and plenty of responsibility. He is thriving in his new job and his

coworkers thoroughly enjoy having him there. Good work Leslie!

Michelle McCary found her dream job a couple months ago. Michelle was hired by Cintas, Corp. as a Linen Folder on June 19, 2007. Michelle had an excellent resume when she hired Melissa to help her find a job. She



had extensive experience working in kitchens as a dishwasher. She had also worked in retail, which she enjoyed very much. The challenge was that Michelle has a touch of Autism and needs a job that is repetitious in nature. During the job search process Michelle came to grips with the fact that kitchen work and retail was a little too hectic and ever-changing. So we started searching for jobs in the warehouse industry.

Cintas, Corp. is a warehouse with many positions that require repetition. Cintas wanted to hire Michelle because of her strong work history. They even adjusted her working hours so she could arrive an hour late due to the bus schedule. Sometimes businesses

are asked to make accommodations for people with disabilities and usually they agree. Cintas also allowed Melissa to job coach Michelle for her first two months. Michelle has been working very hard to meet their standards for productivity. She has improved so much that she no longer needs her job coach.

Supported Employment can fill many job-search gaps for people with disabilities. In Leslie's case, he needed someone who could sign during interviews and advocate for him with employers. For Michelle, she needed someone who could really understand her needs and help her employers and co-workers understand them as well.

To read more success stories like these check out the Supported Employment section of the UCP website: <http://www.ucpaorwa.org>, or call Job Developers, Melissa Miller or Jeff Castagnola at 503-777-4166 or toll free in Oregon: 800-473-4581.

A Dad's Perspective

by Rob Moody

Been a while... so here is a quick update on the Moody family. Connor is now 10 and in his third year of football. Taylor is 13, taller than her mother and still playing softball year around. Jenn is going to be 16 soon and will be a sophomore at the high school. Her challenges have certainly changed with her age. Charlie is going to be 17 and entering his junior year in high school. Karla is still able to stay at home with the kids, and keeps our house somewhere on the continuum between chaos and full-on world war. I am still the lucky SOB that gets to go to work every day.

Jennifer, for those of you that are new to our story, was diagnosed with Cerebral Palsy when she was about four. They added Autism to the mix a little later. She is non-verbal and is in diapers, but can walk (when she wants to), and communicates with us (when she wants to) and eats (seeing a trend here?). For the most part she is a typical teenage girl with the attitude, but without the backtalk! Life is good!

I want to tell you a little about kindness in the context of a story that actually happened to my family. Karla and the kids were in California for Spring Break, visiting the great grandparents. They all went out for dinner and Karla had Jenn in the stroller. An elderly gentleman that knows the great grandparents came over and introduced himself, and immediately took to Jennifer. He spent some time talking to her, and asking questions of Karla. He then proceeded to ask if there was anything that Jennifer needed – because he was somewhat wealthy, and would like to do something to help if there was anything. Karla mentioned that we had been considering replacing the stroller as Jenn was growing out of this one, but were waiting as they were really pretty expensive. He responded with something along the lines of “You go get the stroller you want and send me the bill.” Karla called me, crying and trying to tell me of the enormous gift this man had just promised. We were both truly amazed by the random kindness directed toward our daughter. Thanks to this gentleman, Jenn has a new stroller and he paid the entire bill. Our only promise to him was that we would do our best to help someone else's child somewhere and sometime down the road – to pay it forward.

These brief moments are so important in our lives – not only for those of us that have benefited from the kindness of others, but also for the opportunity to help others in some small (or not so small) way. Whether it is sitting and just listening at the end of someone's long day, or sitting with someone's child for an hour so they can take a walk or go to the store for a break – those can be truly meaningful gifts to a parent challenged with caring for a medically fragile child. I have said before – we are all members of a very special club that nobody wants to belong to. We need to stick together and take care of each other... if we don't, I am not sure who will. We know what each other needs – and we know what it takes. Sometimes it even seems to help our own situations and ease the pain a little bit when we are able to ease someone else's burden.

If we have a chance to pay it forward – we have to seize that opportunity. We have all had an elderly gentleman of sorts that has helped us at some point. Our kids need us, and we need all the help we can get. So let's take care of ourselves and each other...*Rob*

Resources

State Representative Sara Gelser introduced HB 2406, the Medicaid Waiver bill, which was passed by the Oregon Legislature, and will go into effect on January 1, 2008. Below is a synopsis about the bill from her website. It is a huge step in the right direction for families in Oregon.

Medicaid Waiver (HB 2406): Currently, about 80 Oregon children grow up in nursing homes and hundreds of Oregon children are placed in foster care due to their disabilities. (This bill was mentioned in a front page article in the [Wall Street Journal on June 28, 2007](#)). This bill will leverage federal Medicaid dollars at a 2:1 matching rate to allow children with severe disabilities to grow up in their family homes, regardless of income. This will help bring some kids home, prevent further out of home placements, and in the long run save the state millions of dollars. The Legislature allocated \$1.4 million in general funds (which will be matched with federal dollars) for this biennium. The program will begin on January 1, 2008. If you know a child you believe should be eligible for this program, please contact your local Developmental Disabilities office so that you can get more information about the enrollment and eligibility process.

MORE HELP WHEN MEDICAL INSURANCE CLAIMS ARE DENIED:

Oregon Insurance Division: Consumers may ask the Oregon Insurance Division for help with a complaint against an insurance company at any time. Call 888-877-4894 (toll-free in Oregon), or <http://www.oregoninsurance.org/consumer/tomake.html>.

Insurance Division Consumer Protection: If you are having trouble with your insurance company, or would like more information about health insurance coverage, you can contact this agency and speak with a consumer advocate. Contact the Consumer Advocate Unit at 503-947-7984, 888-877-4894 or visit <http://www.oregoninsurance.org>.

DON'T HAVE INSURANCE???

Family Health Insurance Assistance Program (FHIAP) is a state program that helps uninsured Oregonians buy health insurance by giving subsidies to help pay the monthly cost of the health insurance premiums. Information and an application can be found at <http://www.oregon.gov/OPHP/FHIAP/index.shtml>, or by calling 1-888-564-9669.

Equipment Exchange – if you have any walkers or wheelchairs (or other equipment) that your child has outgrown, let us know and we'll see if we can find a child who could use it. While we don't have room in our office to store equipment, we can facilitate equipment exchanges between families. Contact Cari at UCP Family Support: 503-777-4166.

CALENDAR OF EVENTS....CALENDAR OF EVENTS....CALENDAR OF EVENTS

September

- 13 6:30 pm Gimme A Break **Call UCP 503-777-4166**
Monthly Resource & Support for anyone parenting a child with a disability. The topic will be how to deal with long-term stress.
- 19 6-8:30 Switch Workshop – learn how to adapt toys and build switches. Workshop will be held at the UCP office & sponsored by OTAP. Call to register: 503-777-4166.
- 29 all day **Ride Without Limits** – a fundraiser benefiting UCP. It's a scenic bike ride through the Willamette Valley. Call to join a team as a rider or to volunteer as a crew member: 503-777-4166.

October

- 11 6:30 pm Gimme A Break **Call UCP 503-777-4166**
Monthly Resource & Support for anyone parenting a child with a disability.
- 13 10am Oregon Zoo - UCP Family Outing at the Zoo! We have 100 free tickets. Call to reserve yours now. We'll meet at the entrance, and enjoy the zoo – then meet on the grass to enjoy lunch together. Call 503-777-4166 today.

November

- 2-3 9am-3:30pm UCP 12th Annual Family Conference with keynote speaker Geri Jewell at the Red Lion-Jantzen Beach. Two days of workshops, great food, and great friends you haven't met yet. A perfect place for gaining information and making connections. Registration forms online at: www.ucpaorwa.org, or call UCP: 503-777-4166.
- 8 6:30 pm Gimme A Break **Call UCP 503-777-4166**
Monthly Resource & Support for anyone parenting a child with a disability. The topic will be how to handle holiday stress.

December

- 13 6:30 pm Gimme A Break **Call UCP 503-777-4166**
Monthly Resource & Support for anyone parenting a child with a disability. We will have a potluck and enjoy festivities together.

SAVE THE DATE: Mt. Hood Sledding Outing: January 19, 2008

UCP FAMILY CONFERENCE – November 2-3, 2007, Red-Lion Jantzen Beach

Our 12th Annual UCP Family Conference is coming up! We hope you won't miss the opportunity to hear Geri Jewell, our keynote speaker. She will also lead a workshop at the conference.

This is a great opportunity to renew and recharge. You will be inundated with new information, helpful ideas, and strategies that will make your life just a bit (or a lot) easier. Plus you will make new friends and interact with professionals who care enough about our kids to participate in the conference.

Besides the keynote, there will be 15 workshops on a wide variety of topics, including how to get insurance companies to reverse denials, home accessibility solutions, techniques to get your child's physical therapy and speech therapy goals met through play, and new information about changes in the laws that affect IEPs. For a complete listing of the workshops, and a registration form, please visit our website: www.ucpaorwa.org. You will see a link to the UCP Family Conference.