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Promoting Independence, Productivity and Integration for All People

Educating new and expecting mothers

HDI's National Center for Prenatal and Postnatal Down Syndrome Resources

Imagine a woman early in her pregnancy who receives the unexpected results – perhaps through a telephone call while driving or perhaps at work - that there is a strong likelihood that her child will have Down syndrome. The results are from a new test - one of the new noninvasive prenatal screening tests, in which a small sample of her blood had been drawn.

She is frightened and feels very alone. She is not even sure what life is like for children with Down syndrome in today's world. The pregnancy she had expected is gone, and with it, she has only questions and fears about the future.

HDI is leading national efforts to change this picture. Our National Center for Prenatal and Postnatal Down Syndrome Resources (www.downsyndromediagnosis.org) is creating education programs and resources for medical practitioners and for couples receiving a prenatal or postnatal diagnosis of Down syndrome, at this most vulnerable point in their lives. Our role is to ensure that new and prospective parents have access to accurate, up-to-date, and balanced information about Down syndrome and other genetic conditions when they most need that information. Our Center



is staffed by primary author and medical outreach coordinator, Stephanie Meredith (based in Atlanta), our legislative advocacy and bioethics specialist (Mark Leach, a Louisville attorney), and is directed by Harold Kleinert.

Currently, three sets of resources are fully integrated into a seamless portal as the cornerstone of the National Center.

1. “Understanding a Down Syndrome Diagnosis” is a print and digitally published resource for expectant parents immediately after receiving a prenatal diagnosis. The booklet also includes a Spanish translation. It is the only resource for both medical providers and prospective parents that included in its development representatives from the

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A Word from Harold...

A critical function of every University Center for Excellence in Developmental Disabilities is doing research – hopefully, research *that matters*, research that results in direct applications to improve the lives of the people we serve. To that end, HDI has named *both* a new Research Director and created a second research position - Research Analyst/Statistician. Working in tandem, these two new positions are designed to enhance our collaboration with both UK faculty and students, in identifying ways we can expand our research efforts. These two new positions will create a true Research Core for HDI.

Our new **Director of Research is Dr. Malachy Bishop**, Professor and Director of the PhD program in Rehabilitation Counseling, Department of Early Childhood, Special Education, and Rehabilitation Counseling, in the College of Education.

Dr. Bishop brings a tremendous level of research productivity, funded research proposals, and doctoral and masters student mentorship to his new role with HDI. As Director of Research, Malachy will coordinate research efforts within the Institute, including assisting HDI staff in conceptualizing important research questions that can arise from our work; reviewing proposed qualitative and quantitative designs, outcome measures, and proposed journal/presentation submissions; as well helping us conceptualize research grant proposals and make connections to academic departments across campus in this work.

The focus of Malachy's career has been working with children, adolescents, and adults with disabilities and chronic health conditions. Earlier in his career, he had pre-doctoral training at the University of Wisconsin's UCEDD, as a LEND scholar.

In addition, HDI's **Dr. Tony LoBianco** has been appointed to the position of HDI **Research Analyst**

and Statistician. Tony is Project Director for the KY Post-School Outcomes Center (KyPSO) which collects and analyzes life outcomes for all former KY students with Individualized Education Programs (IEPs) one year after they leave school. These data are analyzed and reported to each district yearly to assist them in improving their programs. Under Tony's direction, KYPSO also does research on the important factors that predict post-school success.

Tony has provided assistance to both HDI staff and students for a number of years in both statistical design and analyses of their research studies. This appointment recognizes the importance of this work, and formalizes and expands it across all of HDI. In this role, Tony will provide consultation to HDI staff and students in statistical analyses and designs for research studies, projects, and grant applications; using *large scale data bases* to address specific research questions; and determining *how to link those data sets*, to address research questions that cannot be addressed by any single data set.

Finally, **Ms. Chithra Adams** has been named **Director of Evaluation** for HDI. Under Chithra's guidance, in less than two years, the Evaluation unit has expanded its external contracts to 10 projects, including federal, state and university initiatives.

The Evaluation Unit staff has grown to include three full-time employees, three STEPS employees, and two Research Assistants. The Unit has taken a lead role across HDI in helping our projects develop evaluation measures consistent with our broader HDI evaluation, but that also address the specific needs of each project. Chithra has worked to create a vibrant and dynamic evaluation team, in which each member is respected, valued for his or her contributions, and in which the entire team knows each other's roles. Our Evaluation Unit represents a model of organization and communication that we all should strive for!

HDI National Center (continued from front page)

American Congress of Obstetrics and Gynecology (ACOG), the National Society of Genetic Counselors (NSGC), the American College of Medical Genetics and Genomics (ACMG), and national Down syndrome organizations.

2. “Brighter Tomorrows” is an online English and Spanish resource that provides both prenatal and postnatal support, funded by a National Center on Birth Defects and Developmental Disabilities grant to HDI. The Brighter Tomorrows Family Version (www.brightertomorrows.org) continues to be updated to reflect the most current information prospective parents have indicated they need, as well as “Life Glimpses” of families and individuals who have Down syndrome – the “stories” of their lives.
3. DownSyndromePregnancy (www.DownSyndromePregnancy.org) is an online resource which includes the book *Diagnosis to Delivery: A Pregnant Mother’s Guide to Down Syndrome* available as a free download and through Woodbine House Publishing. DownSyndromePregnancy.org serves as a source of both information and support for women who have recently received a prenatal diagnosis and have decided to continue their pregnancy.

The American College of Medical Genetics and Genomics (ACMG) policy statement (2013) included only three recommended resources for patients receiving a prenatal diagnosis: The statement specifically includes “Understanding a Down Syndrome Diagnosis”, Brighter Tomorrows, and the American Academy of Pediatrics “Health-Care Supervision for Children with Down Syndrome” – we are especially proud that two of those three are part of HDI!

Our work mirrors both federal and recent state legislation. At the federal level, the 2008 Prenatally and Postnatally Diagnosed Conditions Awareness Act (known as “Kennedy-Brownback”) was passed unanimously by both Houses of Congress and signed into law by President Bush. While no funds were appropriated, this bill would have created a national entity to “disseminate current evidence-based information relating to Down syndrome or other prenatally or postnatally diagnosed conditions.” We have tried to do just that.

Meanwhile, states are passing “Kennedy-Brownback” legislation on their own. In 2012, Massachusetts became the first state to require that parents and prospective parents be given up-to-date, evidenced-based information upon a prenatal or postnatal diagnosis. Kentucky became the second state to do so with the unanimous passage (in both our House and Senate) of the “The Down Syndrome Information Bill” (SB 34). Both Kentucky and Massachusetts are using the resources of our National Center to fulfill their respective state laws. This May, two additional states – Delaware and Maryland - passed similar laws, with several other states considering legislation.

There is perhaps no event so momentous as preparing for and experiencing the birth of a child, and there is no time when accurate information is more critical than when new or expectant parents receive news of either a prenatal or postnatal diagnosis of Down syndrome, the most common genetic condition that affects approximately 1 in 660 pregnancies. New and expectant parents need lifelines of balanced information and support right away. That is what the work of our National Center is all about!

Putting faith to work

An HDI partnership with faith community members

A June 6th headline read “Employment Hurdles Remain For People With Disabilities.” The article begins, “Even as some signs point to an improving job market, the unemployment rate for Americans with disabilities is up slightly, the U.S. Department of Labor said Friday.” Despite decades of efforts to improve employment prospects, people with disabilities continue to be relegated to low paying, low status jobs or chronic unemployment. Certainly some gains have been made through the years, but additional innovative employment strategies must be developed. Has too much emphasis been

placed on formal, professionalized approaches within human services and too little thought given to typical, organic, neighborly, personalized ways of finding good work?

A new look at an old issue. Putting Faith to Work is a 2-year initiative sponsored by the Kessler Foundation that’s designed to explore possibilities for people with disabilities pursuing good employment through the supports inherent in their faith communities. Erik Carter, our Vanderbilt *Putting Faith to Work* partner explains, “We are convinced that we must work both within and beyond the formal service system if we’re

Putting Faith to Work (continued from page 3)

going to fundamentally change the employment landscape for Americans with disabilities.” The idea of faith communities assisting members with employment is not necessarily new. However, the emphasis and intent around promoting good employment for a member who has a disability may represent the enlivening or awakening of an idea that’s entirely consistent with the faith community’s mission, but one that has not been previously considered.

Purpose. Societal contribution. Mutual support. All are natural expressions of faith communities. All are essential elements of good employment. A recent *New York Times* article cites a study describing reasons for employee satisfaction including “feeling valued and appreciated for their contributions.” *Purpose* was the study’s single variable having the most significant positive impact: “(employees) doing more of what they do best and enjoy most, and by feeling connected to a higher purpose at work.” The Christian Apostle Paul echoed this sentiment centuries earlier: “*Each person is given something to do that shows who God is: Everyone gets in on it, everyone benefits.*” (1 Corinthians 12:7 MSG) And centuries before Paul, wisdom from the Hebrew Bible describes benefits of good words and good works: “From the fruit of their lips people are filled with good things, and the work of their hands brings them reward.” (Proverbs 12:14 NIV) Employment provides one important way of expressing purpose or vocation in life – doing something that matters.

Other benefits of the Faith to Work approach include networking, the cousin of fellowship within a faith community. It’s widely recognized that networking is a primary way for people getting connected with fitting jobs. Just think of networks contained within members of the faith community, and then the exponential networks that are possible given

people known to members outside of the community.

How does it work? We’re seeking a partnership with faith community members, with and without disabilities. HDI’s Faith to Work coordinator arranges a time and place convenient for member(s) or clergy to discuss possibilities -- exploring ways that honor their faith traditions and culture while pursuing good employment for a member who has a disability.

Who’s involved so far? Connections have been made mostly through members or other personal referrals within diverse faith communities: large and small, rural and urban, theologically conservative or liberal. Christian, Jewish, and Muslim communities are involved in the conversation.

What do we believe will happen? If we’re successful in recruiting and partnering with 15 faith communities in each of the four participating states*, then we’ll have 60 stories about what it looks like for faith communities to support members with disabilities getting good employment. And there will be 60 very diverse examples for other faith communities to model and for the 60 original to continue. There will be another way of innovation to address the very old issue of unemployment or underemployment for people with disabilities.

More information? Please contact Milton Tyree, HDI’s Faith to Work Coordinator, mtyree@uky.edu, (mobile) 502-333-2747.

Four University Centers of Excellence in Developmental Disabilities (UCEDDs) are involved: The Vanderbilt Kennedy Center serves as the lead UCEDD for *Putting Faith to Work*. Other partners include our own University of Kentucky Human Development Institute (HDI), the Texas Center for Disability Studies within the University of Texas, and the University of Minnesota’s Institute on Community Integration.

Kentucky Peer Support Network

Building friendships and expanding inclusive activities for students with disabilities

Both research and the experience of the families we serve tell us that making friends can be especially hard for students with significant disabilities. Peer supports and peer networks can help foster relationships by bringing students together! HDI, through funding from the Commonwealth Council on Developmental Disabilities, is training schools throughout the state to set up Peer Support and Peer Network Programs.

Peer Support and Peer Network programs involve identifying and equipping a group of peers to provide ongoing support to individual students with significant disabilities in or outside of the classroom. Within inclusive classrooms, Peer Support programs train peers (usually 2-3) to provide academic and social support during ongoing learning activities.

KY Peer Support Network (continued)

Beyond the classroom, a group of peers (usually 3-6) form a Peer Network around a student with a significant disability to help foster social connections and friendships between classes, at lunch, in extracurricular activities, or beyond the school day. School staff facilitate these groups to ensure their success. Note that these programs are a step beyond traditional peer tutoring/peer buddy models that many schools use, in that they include multiple peers to support students and, most importantly, they facilitate learning and friendship outside the special education classroom.

There are clear benefits for students with Peer Support and Peer Networks. The structured face-to-face time allows students to get to know each other well, a necessary component for friendship. Participation in enjoyable social events, like sport events and afterschool activities, allow students to have fun and to grow as they are getting to know each other. Peer Supports and Peer Networks can help students become more efficient communicators and increase participation in the classroom. Academic engagement is enhanced, and students' self-confidence and self-determination are increased by the support they receive from their peers.

Typical peers gain benefits through Peer Support and Peer Network programs as well. Students without significant disabilities learn about individuals with disabilities and, in turn, learn a great deal about themselves. They are given an opportunity to build friendships they otherwise may have never had. They may become involved in extracurricular activities they had never considered. Academics are also enhanced—previous research shows that students who themselves were just getting by or even struggling in a class raised their grades by over a full letter grade in classes where they supported a peer with a significant disability!

The Kentucky Peer Support Network Project staff from the Human Development Institute include Dr. Harold Kleinert, PI, Patti Parsons, Project Coordinator, and Katie Hastings, Research Assistant. Our regional and school trainings are led by Dr. Erik Carter of Vanderbilt University. His work focuses on evidence-based strategies for supporting access to the general curriculum and promoting valued roles in school, work, and community settings for youth and adults with intellectual and developmental disabilities.

Regional Trainings are being conducted at nine locations throughout the state in 2014. Encourage your school to attend the



Regional Training in your area to learn more about this exciting project. School teams (including a regular education teacher, special educator, administrator and parent) are being recruited. While one school in each Special Education Cooperative will be selected as a Pilot Site, all teams who attend a Regional Training will receive follow-up through the project.

Regional Trainings have been scheduled for the following Special Education Cooperatives:

Green River Regional Education Cooperative
Wednesday, August 20

West Kentucky Educational Cooperative
Thursday, August 21

Southeast/Southcentral Education Cooperative
Wednesday, September 3

Kentucky Valley Educational Cooperative
Thursday, September 4

Kentucky Educational Development Corporation (Big East)
Friday, September 5

Jefferson County Exceptional Child Education Services
Friday, August 8 (tentative)

For more information, check our website at www.kypeersupport.org, and like us on Facebook (<https://www.facebook.com/kypeersupportnetwork>)! If you have questions, please contact Patti Parsons (ppa245@uky.edu, 859 218-1338) or Katie Hastings (kaha222@uky.edu, 859 257-4460). We look forward to meeting you!

Breaking down the barriers to good health

The importance of finding ways to incorporate healthy habits into everyday life

Everyone, with or without a disability, can find themselves struggling with barriers to being healthy and physically active. However, if you happen to have a disability, the barrier may seem too steep of a mountain to climb. The Centers for Disease Control and Prevention (CDC) identify barriers of healthy living to include physical limitations, pain, low energy, overall lack of resources or accessibility which encompasses issues with finding the time, money, transportation, or even social supports that encourage healthy lifestyle options. So what are the steps in overcoming barriers such as these?

First, focus on what you *can* accomplish instead of worrying about what your limitations might be. More often than not you may end up surprising yourself and do more than you imagined you could. The first step is to take a chance and try. If you can only stand to walk briskly or do chair dancing aerobics for five to ten minutes, then that is a good start and you can increase your time by another minute each time you exercise and before you know it a whole hour may have passed!

When it comes to pain and exercise, it is always important to know the difference between good pain and bad pain. Certain aches and pains in muscles are a sign that they are working and getting stronger. This can be the burning sensation you get on the last few stairs or repetitions in your bicep curl as well as the muscle soreness you feel a day or two after exercising. This pain goes away shortly after you exercise and is triggered by a buildup of lactic acid during activity. Bad pain is often the result of an injury or pushing yourself too hard. This pain may last for a long time, feel constant, and affect your daily activity. You never want to feel sharp pain during exercise. To prevent injury, make sure that you always warm up and stretch, start slow and increase your intensity slowly, drink plenty of water, and make sure to add variety to your exercise routine so you spread the work on your muscles instead of overloading the same spot.

Lack of energy should be a simple barrier to overcome, especially because making healthy choices, including physical activity and a healthy nutritious diet, provides you with a boost in energy and makes you feel better. Motivate yourself to exercise for at least one minute and chances are once you start being active you will keep on going. Hopefully you will go until you meet that 30 minute mark, or longer, and feel so much better that you did.

Barriers such as time and money or transportation are barriers that may require you to look from a different angle. If your local fitness facility doesn't offer an affordable rate, you can look for local walking groups or get creative at home. Also keep in mind the Commonwealth Council on Developmental Disabilities offers a Recreation Involvement Fund. You can learn more about this at chfs.ky.gov/ccdd. The cost of time is worth the benefits, so don't let that hold you back. Even if you get 10 minutes in the morning, and 20 in the afternoon, that still counts! Social supports are more important than people think. Surround yourself with others who strive to make healthy lifestyle choices and you will find that you'll support and motivate each other to be successful. This may also help with transportation issues if you can work together to get to where you need to go for your intended activity. Also remember to be that positive support to others who are trying to make healthy lifestyle choices and encourage them to be healthy. You can lead by example!

Why is Health Important?

When it comes to leading a healthy lifestyle many people can say that they know when something is bad for their health. Yet they continue to engage in that unhealthy behavior (for instance, drinking sugary high calorie soft is a commonly known unhealthy option, though many people still drink them out of habit or because of short-term rewards).

Knowing the long term effects of current negative health decisions is the first step in the battle against an unhealthy nation. People need to know what they are missing out on by passing up the healthy options. Side effects of inactivity and unhealthy diet include obesity and the complications associated with being overweight. This also includes heart issues like high cholesterol and cardiovascular disease, diabetes, higher risk of stroke, depression, and decreased productivity and independence. In 2010, the American Heart Association specified that physically inactive individuals are almost twice as likely to develop heart disease as persons who are physically active. This makes inactivity as serious of a risk factor for heart disease as smoking cigarettes, or having high blood pressure or high cholesterol alone.

Research demonstrates that making healthy lifestyle choices by being physically active and eating a healthy diet can

improve one's quality of life. Benefits include the decreased risk of developing those negative health conditions, losing weight, having more energy, having increased strength and independence, feeling happier and just feeling better overall. We each have the ability to make the decisions to be healthier, we just need to do it!

Healthy Tip for Summer: Stay Hydrated!

With the possibility of record-breaking high temperatures this summer, it is important to remember to drink plenty of water to stay cool and stay hydrated. The Mayo Clinic defines

dehydration as when you use or lose more fluid than you take in, and your body doesn't have enough water and other fluids to carry out its normal functions. If you don't replace lost fluids, you will get



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dehydrated. The general guideline is to drink six to eight 8-ounce glasses of water every day. Signs of dehydration include increased thirst and dry mouth, dry or itchy skin, headache or lightheadedness, dark urine, constipation, and trouble keeping cool.

Also keep in mind that drinking caffeinated liquids like coffee or sodas may make you thirstier or have to use the restroom more frequently and actually cause you to feel dehydrated. It is best to always focus on drinking water to ward off dehydration.

Resources for Healthy Nutrition on a Budget

www.choosemyplate.gov illustrates the five food groups and how to incorporate them into a balanced nutritious diet and has just launched a new module for Healthy Eating on a Budget offering resources on creating a grocery game plan, smart shopping, healthy meal preparation and sample 2 week menu plans with grocery lists

<http://snap.nal.usda.gov>. The SNAP-Ed Connection is an online resource for healthy eating, smart spending on food, and over 600 low cost recipes.

Consumer Advisory Council updates



by Shannon Caldwell, HDI-CAC Liaison, AUCD Council on Community Advocacy Family Co-Chair

Greetings! I hope everyone is having a great summer kick off. Here is what has been happening lately with both our CAC and the

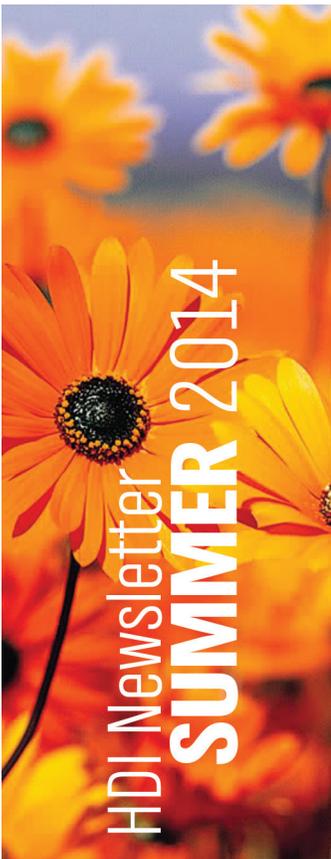
AUCD Council on Community Advocacy (COCA).

Our CAC has been providing guidance and advice to our College and Career Readiness Project (part of the KY Department of Education State Personnel Development Grant). We are truly excited to give valuable input to this vitally important program, which if implemented correctly will have a major impact in individuals' with disabilities and their families' lives and students' ability to go to college or on to careers. We also continue to monitor our yearly progress as mandated by our federal DD Act. We had a fresh new look at our year's progress and reviewed all our projects and gave input as to tweaks and updates needed in our Core workscope.

We want to send out a welcome to all the new additions to HDI in the recent months and thanks to those who are saying goodbye to us. Our CAC also welcomes two new members,

Ms. Jennifer Mynear and Dr. Prema Rapuri, who are both parent members as new members to our CAC. Please join me in welcoming them to our family. Also please thank Ms. Karen Boudreaux and Dr. Malkanthie McCormick for their work on our CAC, as they are leaving us as their terms end. We will miss them and appreciate their service.

Regarding COCA, we have submitted a proposal to present a concurrent session at this year's annual meeting at AUCD on Employment. Several of us are hoping to share our centers' work around employment. As our own CAC has been instrumental in creating our employment page, that should be exciting information to share should our proposal get approved. Proposals were due in June 2nd and we turned ours in. Also we continue to work on a universal ID Card for paratransit users that would eliminate barriers to paratransportation. We also continue our work on CRPD — we remain committed to seeing ratification of rights for persons with disabilities in the world. Finally we are involved in other councils groups and special interest groups at AUCD to advance advocacy around the country. A major strategic plan is being developed as well. Until next time...



The Human Development Institute (HDI), a University Center for Excellence in Developmental Disabilities Education, Research and Service, is about people and the belief that we all deserve the opportunity to be valued, active members of our communities. The Institute's mission is to promote the independence, productivity, and integration of people with disabilities and their families throughout the life span.

HDI is a unit of the Office of the Vice President for Research at the University of Kentucky and part of a nationwide network of University Centers for Excellence. The Centers were established by federal legislation to promote team-based approaches to providing services for individuals with disabilities and their families.

The Institute operates projects in areas such as:

- Technology development and training
- Early identification of children at risk of disabilities
- Promotion and development of school programs that meet the needs of all children in primary through secondary levels
- Employment and living opportunities for individuals with disabilities
- Life-span educational opportunities for individuals with disabilities
- Personal futures planning to identify individual interests and goals for individuals with disabilities
- Training programs to improve the provision of human services for individuals with disabilities and their families.