



LEARNING COLLABORATIVE Youth Transition to Adulthood

Pat Langston

The Title V Program has embarked on an exciting new collaboration with six Oregon counties. In January, we held the initial session of a yearlong Learning Collaborative on Youth Transition to Adulthood. Teams of families and professionals in Coos, Curry, Hood River, Jackson, Lincoln and Union counties participated from their communities in an interactive video conference with participants on site at OHSU. Title V staff, keynote speaker Betty Presler and a panel of youth and parents presented information on promising practices, which the teams used to develop aim statements for their individual communities. This meeting was just the beginning of the Learning Collaborative, which will extend over the next 9 months.

Learning Collaboratives are a nationally tested method that relies on groups learning together and adapting new practices to their settings. This concept was developed by the Institute for Healthcare Improvement (IHI) to increase the rate that promising practice information is incorporated into healthcare settings. Healthcare experts present promising practice information to teams during the initial session, and then the teams meet individually to develop “change” plans for their unique needs.

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Tribute to Kathie Williams

Diane Smith



Kathie Williams, a woman full of charm, poise and grace, has passed away after a five-month battle with cancer.

Many of you have had the privilege of working with Kathie during her 13 ½ of years at the Child Development and Rehabilitation Center at OHSU. In her role as the Director of the Title V Community Connection Network Program (CCN), Kathie established a statewide network of community-based clinics to help children who were not making expected progress or who had unresolved medical issues. Her leadership and innovative approach to the system of care for children with special needs has enhanced the way care is provided to this vulnerable population in Oregon.

Throughout her life, Kathie was active in helping children. Her efforts extended from her work at the Oregon Department of Education in early intervention to CCN and to her international volunteer work in remote villages of Zambia, Rwanda and Senegal. Her leadership and dedication to children extended both locally and internationally through Women of Vision, a local chapter of World Vision which she helped establish that ministers to impoverished women and children throughout the world. Kathie’s career, her volunteer achievements and her devotion to family and friends attest to her unselfish commitment to making the world a better place...and just by having known her we are blessed.

INCIGHT: Resources for Self Empowerment

Scott Hatley, Founder

We are looking for 26 high school seniors to give scholarships to!!

Let me tell you a story about a new non-profit called Incight. This dream started in Portland and is quickly building capacity. We started with 4 high school students with disabilities receiving college scholarships. Our 2005 goal is to provide scholarships to 26 additional students.

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Bob's Corner: *The Director is Usually In* Dr. Robert Nickel, Director

Hi again. It is with heavy heart that staff of the Title V Office said a final good bye to Kathie Williams, a wonderful colleague and friend. We will miss her greatly. A brief tribute to Kathie is included in this newsletter.

Another part of the newsletter highlights a recent activity of the office. OSCSHN staff have just completed the initial session of a yearlong learning collaborative on transitioning youth to adulthood. Teams from six Oregon Communities participated by interactive videoconference.

Certain issues require community solutions and broad representation from a variety of providers and consumers on planning groups. Transitioning youth to adulthood, including adult healthcare services, employment or higher education and independent living is one of these issues. The use of videoconference makes it possible for community teams and healthcare experts to work together. We plan to sponsor other learning collaboratives facilitated by videoconference with community teams in the future, and we will work to support other organizations, for example, the Oregon Pediatric Society, in developing learning collaboratives with primary care practice-based teams.

What are other opportunities for interactive video? The telecommunications infrastructure is largely in place in Oregon. Currently many organizations, including hospitals, are using interactive videoconferences for training sessions, for planning meetings, and for limited clinical activities. We plan to increase our use of videoconferences for our planning meetings and training activities and hopefully cut

travel costs and increase participation. In addition, we will begin to support the use of interactive videoconferences for telehealth through the multi-state Genetics services grant. This grant will provide telehealth access to metabolic geneticists for children with metabolic disorders and to medical geneticists for newborns with congenital defects or apparent birth defect syndromes at a few local sites. For further information about these activities, contact Kerry Silvey, 541-346-2610, ksilvey@uoregon.edu.

In addition, there will be a flurry of activity in the next two months as we conduct the needs assessment for reapplication this spring/summer for the five year Maternal Child Health Block Grant. We are collaborating with staff of the Office of Family Health in this process. We plan to focus our needs assessment activities primarily on identification of health care disparities, capacity assessment related to the CaCoon Program and three of the six rate performance measures for Children with Special Health Needs: adequate financing of needed services; early and continuous screening; and families as partners (specifically on cultural competence in care and cultural diversity of staff). The methods we plan to use are key informant interviews, focus groups and targeted surveys of families and providers. So, we might be calling you. Sit on the edge of your seats.

And as always, please contact me with questions and comments as well as recommendations for topics to address in future columns. You can reach me at: nickelr@ohsu.edu, or 503-494-6961, 1-877-307-7070

*The Swindells Center
and Oregon Parent Training and Information Center
welcome*

Kathie Snow

Family advocate and inclusion specialist

*"Disability is
Natural"*

Friday, March 11 10 a.m. to 3 p.m.
Providence St. Vincent Medical Center, Auditorium
Saturday, March 12 • 10 a.m. to 3 p.m.
Providence Portland Medical Center, Auditorium
FREE! Space is limited. Reserve your seat 503-215-2429
1-800-933-8899, ext. 52429, swindells@providence.org.

FUNDING

Remember that Title V has funding available for various equipment, supplies, and activities through the Family Support Program, Street Rods and Zetosch Foundation Funds. For information, contact the Title V Office:

1-877-307-7070

Patty Day 503-494-8704 dayp@ohsu.edu
Pat Langston 503-494-2765 langstop@ohsu.edu

Voices of Families: Our Family's Experience with Transition

Becky Adelman

I am proud to say that I am the parent of two college students! My son is attending Portland State University and my daughter is attending Johnson & Wales University in Denver, Colorado. While it is wonderful to see them both doing well, we are all still transitioning. And sometimes it's hard to tell who transition affects more, kids or their parents!

My daughter has a significant and rare health condition called cystinosis. It primarily affects kidneys, growth, stamina, vision and she also has learning disabilities. From diagnosis at age 1, we have worked for equal social and educational opportunities and to ensure she understood her condition and the importance of taking care of her health. She managed most of her medications and all of her social calendar well before she graduated from high school. She was actively involved in her IEPs and academic supports from the time she was in middle school. She and her counselor completed a college search and applications. My husband and I were very supportive of her determination to go to college, but were mostly available for consultation *and money*. Her health care team, including a variety of specialists as well as her primary care physician, was also very encouraging and committed to continued involvement while planning transition to adult providers. None of us were in a hurry and expected that we would transition slowly during her college years, continuing with some pediatric specialists while selecting and "trying out" adult providers.

Although we knew the possibilities, we were still unprepared for events that unfolded during the last half of her senior year. Her kidney function deteriorated and she needed a transplant. Luckily, we were able to hold off the surgery until after graduation. As we prepared for the transplant we began to learn how difficult health care transition can be. Aimee turned 18 in February and the surgery was in June. Suddenly, we were being told that she would not be able to go to the children's hospital but would be admitted as an adult and that she would be required to see adult nephrologists instead of the pediatric team with whom she had a strong relationship. She was scared. We were scared. Her future was changing. And in the midst of this, she was supposed to leave the care of her trusted providers because she had a birthday!

With support and strong advocacy from many, we were able to keep her pediatric health care team and the transplant care was done at Doernbecher Children's Hospital. Thankfully, all went well. She left the hospital needing most of her old medications plus a whole new regime of drugs, daily

requirements for care, and extensive monitoring. College had to be postponed until winter term and we concentrated on recuperation.

Although, Aimee had done well with 5-6 different oral medications taken at 6-hour intervals, the new set was not so easy. There were 12-13 drugs taken on various schedules, and one was an injection. The dosages changed frequently. Keeping track of meds, weight, blood pressure, temperature and making sure that we had authorizations and adequate supplies on hand were tasks that required a combined effort from all of us. My husband and I were back to being caregivers and coordinators for a couple of months.

We thought she was ready to start college by winter term. Two days before leaving, a check up showed that her white cell count had taken a serious drop. She was packed and ready to go, had already registered for classes and had her plane ticket. We did a quick follow up test and it was worse. Leaving for college was not a possibility. More change, more disappointment, more doctoring. Staying home with mom and dad was far from the future she wanted!

Finally, in August of 2004, a full year after originally planned, Aimee left for college in Denver. Yes, we still have our Oregon pediatric team and specialty providers that follow her health. Two years ago we would have thought she would have completed transition to adult care by now. We are still working on that change, and are thankful that we did not have to transition to new providers during a health crisis. Now that her health is more stable, she is working to find adult primary care and nephrology in Denver. She is managing her own health and medication regimen, although still needs support in making sure that authorizations and prescriptions are called in before she runs out! The intricacies of health insurance require that parents are still involved and can support Aimee with advocacy *and money*! We have also learned that the health insurance organization that covers us in Oregon operates much differently in Colorado. We thought we had made appropriate arrangements for regular care in Denver, but it didn't work well once she actually tried to use it. Thank goodness for cell phones and e-mail!

Transition is an ongoing process in our family. Our experiences have taught us that sometimes events of life are not under our control and change doesn't always happen according to plan. Our experiences have also helped us develop strength, persistence, and resiliency.

You can contact Becky at 503-494-7657, adelmann@ohsu.u

Learning Collaborative, *continued from page 1.*

Typically, Collaboratives include three learning sessions with planning and implementation periods in between. The teams also meet at least monthly to monitor the results of their plans and to make additional changes as needed.

Collaboratives are based on three principles: 1) Adult learning--national and local leaders provide information and teams decide how to use it; 2) Collaboration--learning across teams occurs when the sum is greater than the parts; 3) Improvement science--new learning is converted into real outcomes.

The first session of the Youth Transition Learning Collaborative was facilitated by Title V Staff. Information on promising practices was presented by Betty Presler, CP Coordinator, Kentucky Shriners Hospital, and consultant to the Healthy and Ready to Work National Center. A panel of young people and parents provided expertise from personal experience. The county teams met individually in the afternoon to apply this information to their individual situations. They developed their own aim or purpose statements, defined measurements for success, identified first steps and then reconvened with the other participants through videoconference to share their plans. Some examples of the aims identified by the teams include: building relationships with all providers; learning about the resources available locally; conducting transition meetings with representatives from all pertinent agencies; and including person centered planning with all students.

Teams will meet monthly with an assigned facilitator who will help them follow through with their plans. Title V staff will maintain contact with the teams through conference calls and listserv communications. Two additional interactive video learning sessions are planned for April and October where teams can present to each other and promote collaborative learning as well as hear new information.

This Learning Collaborative was funded through a Maternal and Child Health Integrated Services Grant. We plan to sponsor other Learning Collaboratives with community teams in the future and will work to support other organizations in similar efforts. For more information about this project or Learning Collaboratives in general, contact:

Pat Tangeman, Project Director
tangeman@ohsu.edu, 503-494-3232

Barbara Dworschak, Project Coordinator
dworschak@ohsu.edu 503-494-6208
1-877-307-7070.

Voices of Families

Another Family Story - The College Experience of a Child With a Learning Disability

As told by Evelyn Lowry

Tom was an average boy growing up. He liked to play with his three brothers, two older, one younger. He loved to talk to his parents and would often stay up a little later to spend time with his mom and dad. However, reading was always a challenge. He couldn't seem to keep up with his peers and was getting further and further behind as he advanced in grade level. Subjects that came easily to other students were difficult for him. Eventually, Tom was diagnosed with a "language disability". His mother and father spent a lot of time talking to teachers and other school personnel to get him extra assistance. They paid for tutors. They attended seminars and read everything they could find about learning disabilities. They met with the IEP team and wrote goals and objectives along with the team to provide extra support for Tom.

Although Tom had many strengths, including the ability to memorize details like place and phone numbers, he struggled in school. Other kids made fun of him and school became a nightmare existence. School personnel seemed insensitive to Tom's struggles and did not respond to Tom's parents' advocacy. When he was in high school, Tom's parents decided to remove him from public school and enrolled him in a private school for students with learning difficulties. This school was a great match for Tom. He gained confidence and many skills that enabled him to work at grade level and even excel in some areas. After returning to public school with the skills he had obtained, Tom was able to graduate with his class and apply to college. Unfortunately, this is not the end of the story.

College for many students, whether or not they have a disability, can be a scary and difficult place. Tom had to cope with the usual problems— roommate issues, food, study time and the dorm noise level. Tom however, had the added challenge of not always understanding the professors' lectures and study materials. Taking tests in specific formats was very difficult. Tom tried to get help from study centers. These offered a variety of responses to his requests from "we can't help you" to "go talk to the teacher."

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Youth Transition Resources

Where do I find information about transition from high school to post-secondary education and/or employment?



- **JAN** is the **Job Accommodation Network**, an international toll-free consulting service that provides information about job accommodations and the employability of youth with disabilities. Reach them at 1-800-526-7234 or www.jan.wvu.edu.
- **National Collaborative on Workforce and Disability** is a national technical assistance center designed to assist the workforce development community. It is based at the Institute for Educational Leadership in Washington DC. Information available at www.ncwd-youth.info or you can reach them toll free at 1-877-871-0744.
- **National Center on Secondary Education and Transition** coordinates national resources, offers technical assistance & disseminates information. It is based at the University of Minnesota's PACER Center and can be found on the web at www.ncset.org or by phone at 1-612-624-2097.
- **Oregon's Department of Education** maintains a "Transition Toolbox" newsletter that includes current information regarding various tools, resources specific to Oregon. This can be found at www.ode.state.or.us
- **The George Washington University Heath Resource Center** maintains excellent information about financial aid for students with disabilities (www.heath.gwu.edu).
- **Social Security** offers information on the web or by phone about the application process for Supplemental Security Income (SSI) as well as their "Ticket to Work" program and their PASS (Plan for Achieving Self Support) program. You can reach them at 1-800-772-1213 or www.ssa.gov.
- **Incight** is an Oregon-based service agency focusing on helping youth identify the necessary steps for reaching their goals through specific programs: providing mentoring relationships, college preparation, transition planning, college scholarships, internship opportunities and empowerment skills trainings. Learn more at www.incight.org or call 1-971-244-0305.
- **Project Tech Link** (Virginia Commonwealth University) has a mission of linking educators & parents to "transition best practices" through computer technology. Reach them at www.vcu.edu/rrtcweb/techlink
- **Oregon Colleges/Universities Disability Services** Campus Disability Services promote supportive, accessible, non-discriminatory learning and working environment for students, faculty, staff and community members with disabilities. Disability Services Offices for Community colleges, State Colleges and Universities, and Independent Colleges can be found on the ODE website:
www.ode.state.or.us/links/disability
- **Oregon's Office of Vocational Rehabilitation Services (OVR)** assists Oregonians with disabilities to achieve and maintain employment and independence. Services include: Vocational Counseling and Guidance; Evaluation; Physical Restoration; Vocational and other training services; Information and referral; Job Development and Job Search Assistance. www.dhs.state.or.us/vr/
- **Transition Services, in Family/Educator Guide to Washington's Special Education Services**, contains information on What to Expect, Questions to ask, and Things to Do Together, www.arcwa.org/fepppublications.htm **Available in Spanish, Russian, Cambodian, Vietnamese, Korean and English**

Youth Transition Resources

Where do I look for information to assist me in the transition from pediatric to adult health care?

- **The University of Washington & the Washington State Department of Health sponsored the Adolescent Health Transition Project** creating a wonderful notebook that is entirely available on the web at <http://depts.washington.edu/healthtr>. This includes their outstanding [Adolescent Autonomy Checklist, Transition Timeline \(Available in Spanish, Russian, Chinese, Vietnamese and English\)](#) and articles titled “Transition Includes Preparing for Health Care” and “Getting Excellent Medical Care for the Adult with Developmental Disabilities”.
- **The Healthy and Ready to Work National Center** offers comprehensive information focused on supporting youth’s understanding of systems, accessing quality health care and increasing the involvement of youth at all levels of decision-making. There are links to various tools regarding identifying physicians, health insurance decisions to be found at www.hrtw.org.
- **Health Care Transitions web site** offers information on health care transition for youth with disabilities and special health needs: <http://hctransitions.ichp.edu>.

I want to learn more about how to foster a sense of self-determination!

- See the reference to **Incight** above.
- The **National Youth Leadership Network** promotes leadership development, education, employment, independent living and health and wellness among young leaders. Reach them at www.nyln.org.
- There are some different web sites devoted to the process of person-centered planning or essential lifestyle planning : www.elpnet.net or www.allenshea.com
- **The University of South Carolina** maintains a list of Self-Advocacy and Self-Determination Resources available at the Center for Disability Resources Library: uscm.med.sc.edu/CDR
- There are **7 Independent Living Resource Centers** in Oregon, you can find them at www.ilusa.com
- **Kids As Self Advocates** (a project of Family Voices) is a network of youth with special needs whose mission is to support self-determination, creating supportive networks and proactive advocacy. Reach them at 1-773-465-3200 or www.fvkasa.org.
- **Oregon Parent Training & Info Center** offers Peer Mentor Self-Advocacy Transition workshops statewide. Contact Judy Rinkin at 1-888-505-2673 ext 202.

What about supportive resources for parents of youth with special needs?

- **The Pacer Center** (Parent Advocacy Coalition for Educational Rights) in Minnesota offers lots of good resource information at www.pacer.org. **For information available in other languages, go to: www.pacer.org/publications/multicultural.htm**
- **The National Dissemination Center for Children with Disabilities** is a national information & referral center providing information on disabilities and disability related issues at www.nichcy.org
- **Family Village in Wisconsin** has a comprehensive list of transition resources at www.familyvillage.wisc.edu
- **The Institute on Community Inclusion** offers a wide range of publications and videos under the category of “Education & Transition/Person-Centered Planning” at www.communityinclusion.org/publications.



INCIGHT, *Continued from page 1*

To date Incight has raised over \$40K in grants from names like Nike, Standard Insurance, the Christopher Reeve Paralysis Foundation, Meyer Memorial Trust, and the Juan Young Trust to name a few!

Our mission is to educate and employ people with disabilities. Our goal is to change 2 statistics facing this population: to decrease the unemployment rate believed to be between 44% and 70%, and to improve the 16% college completion rate for persons with disabilities.

Our focus at Incight has been on the high school transition piece for youth with disabilities. Currently students with disabilities are not getting to college campuses. We need to help youth dream big! Incight helps each youth identify the necessary steps for reaching their goals through specific programs that provide mentoring relationships, college preparation, transition planning, college scholarships, internship opportunities, and empowerment skills trainings.

One of the key parts of Incight's mission is in the word **HANDICRAP** about which you can find more information in our brochure. The way we define "handicap" is anything that keeps a person with a disability (or a person without a disability, for that matter) from moving beyond their boundaries and succeeding in life. So, how we're helping youth deal with "handicap" is by creating a program called Empowerment Skills Trainings.

HANDICRAP :
anything that keeps
a person with a
disability from
moving beyond their
boundaries and
succeeding in life

It is designed to bring high school students together in small groups to understand the areas of "handicap" (self-imposed barriers) in their life. It's designed to be life-changing and give students a new perspective on life. The biggest challenge we're solving is helping them realize what's possible.

We realize that the key players needed to make this dream/story happen are in several areas. We've found that there is strong need for an intermediary-type of organization, and that is Incight. It is important to first and foremost build relationships with students and their families. For more information on research about intermediaries, please view the NCS Issue Brief 1.3. at the link in the parenthesis (www.ncset.org/publications). Other important partners are: High school staff/transition staff; College Offices for Students with Disabilities/Admissions; Oregon Mentors (www.orientors.org);

Funding Sources/Grantors/Foundations/Corporate Funds.

Incight is still a rather small non-profit organization in the Portland metropolitan area but we are quickly building capacity. We believe we not only have a strong model for working with the high school population in Oregon, but also a promising national model. We dream of changing the world! We would love to have you be a part of this.

Currently, we are looking for 26 high school seniors planning to go to college next year to give scholarships to!!

Please contact Incight for applications:

733 SW Oak Street, Suite 200

Portland. OR 97205

971-244-0305 www.incight.org

Another Family Story , *Continued from page 4*

Students with learning difficulties need concrete answers and specific suggestions. They are already struggling with lack of confidence. Also, it is difficult for parents to provide the support for their college age student. Parents are not always close by. Students are struggling with their impending independence and don't want to rely on Mom and Dad for support. Still, as a parent, it is hard to watch your child struggle and not want to step in and help.

Tom is continuing his education. He has changed his housing to a single room (no roommate). He is seeking out help from student services for study and testing assistance. Mom and Dad are doing their best to let Tom advocate for himself while still providing the support he needs to be successful. What a challenge!

Although this story is true, the names have been changed. You may contact Evelyn in the Family Involvement Network, (FIN) at CDRC , 503-418-1476 lowrye@ohsu.edu

Oregon Services for Children with Special Health Needs
Child Development and Rehabilitation Center
Oregon Health & Science University
707 SW Gaines Rd
PO Box 574
Portland, OR 97207-0574



Statewide Conference
Embassy Suites Hotel
Tigard, Oregon

The focus of this two-day conference will be on the psychological growth and functioning of children with special health conditions, highlighting the interaction between chronic health issues and psychological risk factors, adjustment problems and related disorders. The content will address the complexity and promise of bringing together approaches in medicine, mental health and education to address the psychological needs in children with special health conditions.

For more information, e-mail
schleyc@ohsu.edu or call Charlotte
Schley at 503.494.4587

Please send us your E-mail address.

To save postage and printing cost, we want to send the newsletter to you electronically in a pdf format. If you have an E-mail address, please send it to Char Schley at schleyc@ohsu.edu.

If you wish to be taken off our newsletter mailing list, please contact Char by e-mail or phone:
1-877-307-7070 x4-4587

**We welcome your
comments and
submissions.**

**Deadline for submissions
to the May 2005 edition
is April 1, 2005**

Contact Information



Community Connections Network
503-494-4586



CaCoon Care Coordination Program
503-494-4219



Oregon Medical Home Project
503-494-3232



**FISHs: Framework for Integrating
Special Health Services**
503-494-3232



FSP - Family Support Program
503-494-8303



FIN - Family Involvement Network
503-418-1476

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