

## FIN: Family Involvement Network

Becky Adelman, Team Leader

Our Family Involvement Network is working hard to bring family perspectives to the Title V Programs and to support families as partners throughout the state. Family Consultants Becky Adelman, Evelyn Lowry and Theresa Rice have extensive experience with special needs children and youth, both as moms and as advocates within the developmental disabilities, health care and mental health service systems.

Since Evelyn and Theresa joined our staff in January, the three family consultants have been very busy. Each of them is actively involved in parent groups and working for initiatives. They have attended and presented at family conferences, including Wagonwheel, the Arc State Conference and the Building on Family Strengths National Conference. In addition, they share their family perspectives with educators and other professionals. They have participated in training activities for students in the OIDD LEND Program at OHSU and in special education teacher courses at Portland State University.

One of the primary goals of the FIN network is to connect with families throughout the state and to develop groups

of parents who will be active partners with professionals and mentors to other families within their own communities. Our family consultants are collaborating with other family groups and professional staff to organize workshops, develop curriculum and share experiences that will help families gain the skills and the confidence to be effective team members. FIN also is developing a web site and listserv that will provide another avenue to connect with families and share information.

Within our OSCSHN Office, parents are participating on all committees, work groups and initiatives. Families are key partners in the Oregon Medical Home Program and the Framework for Integrating Special Health Services (FISHS) grants. We are committed to family involvement at all levels. We will work to ensure broad representation of families and to build the family professional partnerships that will improve health care and services in Oregon.

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## Adolescent Transition

Kathleen Williams, MS

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SEXUALITY & TRANSITION  
VOICES OF FAMILIES

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There are many key transition times in a person's life. Beginning school, starting high school, taking that first job, dating for the first time, moving to a new location to name a few. But transitioning from adolescence to adulthood can be particularly problematic.

Adolescents have a lot going on. They are forming their own identity, increasing their responsibility & independence, separating from parents/families, becoming sexually mature, developing closer peer relationships. They must face issues of sex, drugs, alcohol, and smoking. For adolescents with disabilities these typical features of adolescence are exaggerated by cognitive and physical disabilities. They may lag behind in development and face the stigma and social attitudes toward individuals with disabilities.

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## Adolescent Transition Continued from page 1.

Schools and other agencies help youth with disabilities and their families transition to adulthood. They assist with transition to work for post-secondary education by developing curriculum so it is possible, by providing supports in the workplace, by planning for moving from home to independent living, and by considering any transportation and recreation needs.

But what if there are health issues? Young adults cannot work or move to independent living if they are not healthy. And there is a consensus that youth with special health needs should transition to adult providers. (Society for Adolescent Medicine, 1993; American Academy of Pediatrics, 1996). Pediatricians know childhood chronic health conditions but have not been trained in adult disease. Yet ninety percent of children diagnosed with a chronic illness survive into adulthood (Blum, 2001).

There are several barriers to health care transition. Adult providers lack preparation and training with pediatric-onset conditions and information about what is necessary for effective transition. Pediatric providers are unfamiliar with adult and aging conditions, yet can be reluctant to let go of long term patients. Parents and youth who have developed

a long-term positive relationship with a pediatrician can also be reluctant to change providers. Insurance changes, lack of health coverage, inability to pay also complicate transition.

Oregon's Services for Children with Special Health Needs works to address these issues and barriers through:

- Integration of health into adolescent transition planning
- Development and dispersal of resources and information around effective adolescent transition
- Identification and development of resources for community use
- Training of medical providers, public health nurses, parents and youth as well as community-based multidiscipline teams

Much more work needs to be done. We look to our community partners to guide our efforts.

*Kathy Williams has recently retired as Program Director of CCN. We thank her for her years of service to the Title V Programs and to Oregon families and communities. We wish her well in this key transition.*

## SEXUALITY: Resources for Physically or Developmentally Challenged Adolescents Susan Labhard, MSN, RN

Of all the issues that physically or developmentally challenged adolescents face, the topic of sexuality is often overlooked or “deferred” by parents and health care providers. Adolescents with special needs tend to learn about sex mostly from their able-bodied caregivers. If the information is lacking or does not meet certain needs or expectations, the teen will find out about sex elsewhere (if able), and information could be harmful or incorrect.

It is important to find a way to initiate a talk about sexuality early in the teen years. The Sexuality Reference/Resource List (see Insert) is an excellent start in opening a discussion on this topic and becoming familiar with the great medical progress that has been made. Many parents find it helpful to bring up sexuality issues as a scientific topic or connected to something in the news. Sometimes it is good for the health care provider to give a resource and inform the teen — “we can talk about this next visit if you like.” Providers should respect the confidentiality of the adolescent and provide a time alone for questions and answers.

Family Planning is a great first step. Teens need to know how easy it is to get pregnant. It is vital to consult with a

physician, gynecologist or urologist *before* the adolescent becomes sexually active. Disease prevention is also important to consider *before* having sex. There are many medications and devices on the market and a qualified professional can assist in making the correct decisions about use. Genetic counseling is also a consideration for some individuals.

The Reference and Resource List provided here contains sites where youth get answers to confidential questions. It also has references that offer tips on how to begin conversations about sex with adolescents.

A tip for the “teacher”—be comfortable with your own sexuality first! If it is difficult to discuss, then find someone who can do so comfortably, or provide the proper references and resources. If we do not initiate the discussion or provide references for adolescents with special needs, they may eventually discover this on their own in a manner that is not desirable or safe. We have brought the adolescents on their journey this far, lets help them with this “final frontier!”

*Susan Labhard is a Nurse Manager at Shriners Hospital in Portland*

# Voices of Families

## Jeff's Transitions

Evelyn Lowry, FIN Family Consultant



At 21, my son Jeff has gone through many transitions throughout the years. As a parent I have both participated in these and stood on the sidelines. In writing this article, I have tried to examine my feelings and my decisions in each of the steps that we have taken in order to share them with you. I will try to share with you the things I have done along the way that helped Jeff and our family.

First of all, you need to know that Jeff has moderate mental retardation, mild cerebral palsy and a seizure disorder. He is a fantastic young man with a kind loving disposition. He can also be lazy. His favorite thing to do is to watch television or movies or play video games. That being said, we have often had to push him in order to get him to move on to the next step. Today, he is working part time (20 hours a week) and living in his own town house. He has friends with and without disabilities that are very important to his life.

I have learned that planning is necessary in order to successfully transition to the next phase of our lives. That is true for anyone. However, when children with special health care needs are involved, it takes planning and help from health care professionals in order to make the transitions in life easier. As Jeff moved through the stages of his schooling, preschool to elementary, elementary to middle and middle to high school, we made provision in his IEP to monitor his seizures, provide OT and PT for upper body strength and fine motor development and speech therapy for communication and intelligibility. We worked with family and friends to provide social outlets, explored the community, the Arc, Boy Scouts and Special Olympics in order to teach social skills and self-confidence.

As Jeff was moving into adulthood, we knew that he needed to see himself as an adult, not a child. Too often, people with mental retardation are viewed as grown children. They never make the transition into adulthood. One way to facilitate that transition is to move from a pediatrician to an adult care health provider. Although, for us, this meant taking everyone, doctor, parents, child, out of their comfort zone, we proceeded with this plan. I called or e-mailed everyone I knew for information. Who were their sons or daughters going to for medical care? Who were the

adult providers out there who were comfortable with mental retardation? After getting a few names, I checked with our health insurance policy and interviewed the doctor. The doctor we chose is on a bus line, on our health plan and seems reasonable comfortable with Jeff and his disability. It would have been wonderful to have a list of doctors in advance that practiced adult medicine and were also comfortable with developmental disabilities.

Never forget your dreams and hopes for your child. This is a mantra that I say to parents and myself over and over again. Every parent wants their child to succeed. We dream about the future and try our best to prepare our children to be successful and happy. It is just as important to have dreams for children with special needs as for any other child. The key is to work towards that dream and to get key support people to help. When Jeff was 6, my husband and I dreamed that he would be working and living on his own. All of our IEP goals, transition plans and support services have been gathered with that dream in mind. Parents and young adults must plan for and gather supports around health care as well as employment, social and recreational needs and housing in order to plan for successful transitions throughout the years.

There will be mistakes, frustrating moments and times when tasks seem overwhelming. I can't say I still do not have those moments. We continue to support Jeff. We continue to put pieces of the puzzle together. I imagine that will be the way of life for everyone in my family for many years to come. We have made and lost friends along the way because of our need to support and advocate for our son. However, when I look at Jeff, at his successes and accomplishments, I know it was all worth it.



*Evelyn is the mother of Jeff, and also Sarah, a freshman at University of Denver. Evelyn is currently involved in Washington County DD council, Accessibility Council and Lifespan Respite Advisory Board.*

# SEXUALITY REFERENCE LIST

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- **Human Sexuality Handbook: Guiding People Toward Positive Expressions of Sexuality**. (Available from The Association for Community Living, Springfield, MA, 1985).
- Kriegsman, K., Zaslow, E., D'Zmura-Rechsteiner, J. (1992). **Taking Charge: Teenagers Talk About Life & Physical Disabilities**. Woodbine House, Inc. ISBN 0-933149-46-8
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- Moss, K. & Blaha, R. (2001). **Introduction to Sexuality Education for Individuals Who Are Deaf-Blind and Significantly Developmentally Delayed**. (Available from DB-Link, 345 N. Monmouth Ave., Monmouth, OR 97361).
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- Sloan, S., Leibold, S., & Henry-Atkinson, J. **Sexuality and the Person with Spina Bifida**. (Available from Spina Bifida Association of America, 4590 Mac Arthur Boulevard NW, Suite 250, Washington DC 20007-4226. Phone: 1-202-944-3285 or 1-800-621-3141).
- \*\***Spinal Network**. Nine Lives Press, P.O. Box 220, Horsham, PA 19044. Toll Free 1-888-850-0344, ext. 109 (Fax 215-675-9376). ISBN 0-9715223-0-8
- Young ASBAH Series (1983). **Sex for Young People with Spina Bifida or Cerebral Palsy**. (Available from Association for Spina Bifida and Hydrocephalus, Tavistock House North, Tavistock Square, London WC1H 9HJ). ISBN-0-906687-03-9

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# RESOURCES

- **AIDS HOTLINE:** PHONE: 1-800-342-AIDS (RESOURCE FOR QUESTIONS RELATED TO HIV & AIDS PREVENTION).
- **American Association of Sex Educators, Counselors, and Therapists:** 435 North Michigan Avenue, Suite 1717, Chicago, IL 60611. Phone: 312-644-0828.
- **American Board of Sexology:** 1929 18<sup>th</sup> Street NW, Suite 1166, Washington, D.C. 20009. Phone: 202-462-2122.
- **Coalition on Sexuality and Disability:** 122 East 23<sup>rd</sup> Street, New York, NY 10010. Phone: 212-242-3900.
- **Good Vibrations:** 1210 Valencia Street, San Francisco, CA 94110. Phone: 1-800-289-8423 (e-mail: [www.goodvibes.com](http://www.goodvibes.com)). "Retail store & sex product catalog with a classy touch" per: Kroll & Klein.
- **\*\*Handicap Introductions (Date Able):** International Computer Matching, 35 Wisconsin Circle, Suite 205, Chevy Chase, MD 20815. Phone: 301-656-8723.
- **National Spinal Cord Injury Association:** 245 Concord Avenue, Suite 29, Cambridge, MA 02138. Phone: 617-441-8500.
- **National Spinal Cord Injury Hotline:** 2201 Argonne Drive, Baltimore, MD 21218. Phone: 1-800-526-3456.
- **National Information Center for Children and Youth with Disabilities (NICHCY):** Box 1492, Washington, DC 20013. Phone: 1-800-999-5599.
- **\*\*\*New Mobility:** No Limits Communications, P.O. Box 220, Horsham, PA 19044. Phone: 1-888-850-0344 (e-mail: [www.newmobility.com](http://www.newmobility.com)). Magazine has information on disability lifestyle, culture & resources (i.e., bimonthly column on sexuality and the magazine's annual "Sex, Wheels & Relationships" issue). Contact the New Mobility Bookstore for Sexuality After Spinal Cord Injury and Women With Physical Disabilities plus other references on sexuality. Phone: 1-800-543-4116.
- **\*\*Parent Advocacy Coalition for Educational Rights (PACER Center, Inc.):** 4826 Chicago Avenue S., Minneapolis, MN 55417. Phone: 1-800-848-4912.
- **\*\*Planned Parenthood:** National Headquarters, 810 7<sup>th</sup> Avenue, New York, NY 10019. Phone: 1-800-829-7732. (Local Information on Birth Control--consult the Telephone Directory "Business" section).
- **\*\*??Questions??:** Readers of New Mobility "Love Bites" section are invited to send questions to Lizzi McNeff ([mcneffea@qwest.net](mailto:mcneffea@qwest.net)) or Mitch Tepper ([mitch@sexualhealth.com](mailto:mitch@sexualhealth.com)). Include e-mail address, questions answered online.
- **\*\*Sex Information and Education Counsel of the United States (SIECUS):** 130 West 42<sup>nd</sup> Street, Suite 350, New York, NY 10036-7802. Phone 212-819-9770 (e-mail: [siecus@siecus.org](mailto:siecus@siecus.org)).
- **\*\*Sexual Health Network, Inc.:** Visit the website: [www.Sexualhealth.com](http://www.Sexualhealth.com)
- **\*\*Spina Bifida Association of America:** 4590 Mac Arthur Boulevard NW, Suite 250, Washington, DC 20007-4226. Phone: 1-800-621-3141. E-mail: [www.SBAA.org](http://www.SBAA.org).
- **The Disability Rag:** Avocado Press, Box 145, Louisville, KY 40201. Phone: 502-459-5343.

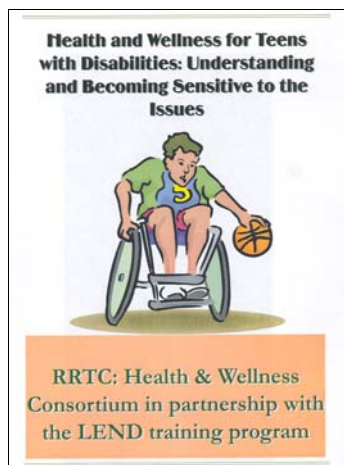
Updated 3/03

Susan Labhard, MSN, RN

Shriners Hospital for Children

# Transition Resources

## Training Module for Professionals: *Health and Wellness for Teens with Disabilities: Understanding and Becoming Sensitive to the Issues*



This training provides a forum for professionals to become sensitized to issues of health and wellness for teens living with disabilities. Discussion includes identification of warning signs about lack of wellness, avenues for increased health and wellness and clinician involvement in creating opportunities for wellness in teens. Modules in the training manual include: *Health and Wellness, Relationships and Sexuality, Mental Health & Substance Abuse, and Nutrition and Physical Activity.*

There are two primary goals of this training.

1. To increase the understanding and sensitivity of health care professionals to issues of holistic wellness for teens with a disability and their families.
2. To increase the comfort level of health care professionals in approaching and talking with teens about a variety of topics that may be considered to be of a sensitive nature.

The authors state that clients often report that health care providers treat their disability more than their whole self. This ultimately inhibits the amount of information that the health care professional gathers from the client as well as how seriously the client takes the provider's suggestions. As a provider, being well-informed about the full life of the teen will not only enhance the ability to assist adolescents in creating wellness in the present, but will positively impact the ability to assist with their overall health in the long term.

This training project was developed by The Rehabilitation Research and Training Center (RRTC) in conjunction with the UAP/LEND training program. To obtain a copy, contact RRTC by e-mail: [rrtc@obsu.edu](mailto:rrtc@obsu.edu), or call Laura Hammond at 503-494-3882. To learn more about the RRTC, visit [www.healthwellness.org](http://www.healthwellness.org).

## Brokerages: Self Directed Support Services

A brokerage is an agency that contracts with the county Developmental Disability Office to provide support for an individual with a disability. Brokerages employ Personal Agents that meet with families and individuals to assess their needs and match them with available services. The individual must meet eligibility requirements for developmental disabilities, must be at least 18 and must live in Oregon.

This process is person centered and family friendly. Personal agents meet the individual and/or family in a location and time that is convenient for them. The planning process is designed to assist individuals and their families to determine and oversee the supports that they need to live the lives that they choose. Services must be based on the principles of self determination.

Brokerages are supported by state general fund dollars as a result of the Staley Agreement. In 2000, five families and the ARC of Oregon successfully filed a lawsuit against the state of Oregon that claimed they were unfairly denied access to services. *Staley v. Kitzhaber* became a successful class action that represented over 3,000 Oregonians with developmental disabilities.

There are nine supported brokerages in five established regions in Oregon. For locations, contact information, eligibility and the background of the Staley settlement, refer to the Arc of Oregon website: [www.arcoregon.org](http://www.arcoregon.org).

# Transition Resources

The  
**Arc**

## A Family Handbook on Future Planning

Available on-line at <http://www.thearc.org/publications/futureplanninghandbook.doc>

A guide to help families develop a future plan for their sons or daughters with cognitive, intellectual or developmental disabilities that provides personal, financial and legal protections for these individuals after the parents either die or can no longer provide care or support. It is a comprehensive guide that will help families review and inventory the needs and strengths of their family member, determine what should be in a plan and then locate qualified professionals and resources to finalize the plan. It includes an overview of planning, information on financial planning for future needs, trusts, guardianships and alternatives to guardianships, preparing a will, government benefits, preparing to work with an attorney, a planning checklist and resources.

**Future Planning: Making Financial Arrangements with a Trust** [www.thearc.org](http://www.thearc.org)

**View Online: *CELEBRATING SEXUALITY--Issues, Strategies and Resources Related to Individuals with Developmental Disabilities***, An Instructional Media Resource from the University of Miami Dept. of Pediatrics Archives on Demand. View at <http://pediatrics.med.miami.edu/IMR/archives.htm>

This two part presentation gives an overview of specific issues relevant to individuals with developmental disabilities, special issues, suggested strategies in addressing these issues, and specific resources that may be helpful when addressing sexuality issues. One objective of the video is to provide a framework for promoting healthy sexuality for individuals with developmental disorders, a subject that has been ignored for decades.



**Marilyn K. Volker, Ed. D., Sexologist**



**Martha E. Sheldon, MSW**

## Passage to Independence Project (PIP)

This is a program for people with disabilities who receive SSDI or SSI benefits. The mission of PIP is to educate individuals about their benefits so they can make informed decisions about work.

- PIP provides free assistance to people with disabilities who want to understand their benefits and learn how their benefits could be affected by work.
- PIP staff work one-on-one with each individual who requests assistance.
- This process is called Benefits Planning, Assistance, and Outreach.

Funded by the Social Security Administration, PIP is an independent program of Oregon Advocacy Center, a not for profit organization which works to defend and promote the rights of individuals with disabilities. For more information, visit <http://www.oradvocacy.org/bpao.htm>, or contact the Oregon Advocacy Center at (503) 243-2081, 1-800-452-1694, Voice; (503) 323-9161, 1-800-556-5351 TTY.

## CAREER JOURNEYS

### WEB BASED CAREER MENTORING FOR YOUTH WITH DISABILITIES

The Center on Self-Determination and Independent Living Resources are proud to announce Career Journeys, a web based mentoring program designed for youth with disabilities or other challenges who are interested in learning about how to choose and achieve career goals.

The purposes of the Career Journeys are:

1. To help youth to believe that they can aspire to the full range of careers and occupations.
2. To provide youth with the opportunity to gain advice, support and mentoring from one or more adult mentors through e-mail conversations.
3. To share the stories of youth who are taking their own Journeys.

To learn more about Career Journeys, visit the web site at <http://www.everyonecanwork.org>

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1-877-307-7070 x4587

*We welcome your  
comments and  
submissions.*

## Contact Information



**Community Connections Network**  
503-494-4586



**CaCoon 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**  
503-494-8704



**FIN - Family Integration Network**  
503-494-7657

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