Transition from adolescence to adulthood is a complicated process for any young person and their family. Where to live and whom to live with; finding a job or meaningful day time activity; whether job training or higher education is the right choice — these are decisions all young people and their families face. For young adults with disabilities, the challenges may be even more difficult and complex. Students who received individualized programming under IDEA in high school may be unprepared for the lack of opportunity in higher education or postsecondary training programs. Families who were comfortable with their pediatrician may be suddenly faced with an adult health care system and providers who are unfamiliar with addressing the needs of adults with developmental disabilities.

In addition, children who were eligible for a wide array of health and related services under the Early Periodic Screening and Diagnosis and Treatment provisions of Arizona’s Medicaid System, AHCCCS, may now be entitled to much less as adults (for example, dental services and incontinence briefs are currently unavailable to adults on AHCCCS). With unemployment hovering at 9.5% and the economy impacting developmental disability and vocational rehabilitation services, young adults with disabilities may have a harder time than ever obtaining employment. Independent and living support options are likely to be fewer as well.

In this issue of Sonoran UCEDD News, we address several aspects of transition for youth and young adults with developmental disabilities, including practical approaches for success in crucial areas, such as – health care, employment, higher education and independent living. Through our work and the work of others throughout the state and country addressing these important issues, we hope to remove barriers and increase opportunities for youth and young adults with developmental disabilities in our communities.

Leslie Cohen, JD
Director, Sonoran UCEDD

Tamsen Bassford, MD
Principal Investigator,
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Youth with disabilities face many challenges when transitioning from the pediatric to the adult medical system. Often the transfer of care to adult or family medicine includes a loss of specialized services.

The transition from the youth medical system to the adult medical system can be associated with moving from a more structured and integrated medical system where youth receive coordinated services to an adult system where practitioners are working independently of each other.

Health care transition can be a time of particular vulnerability. To ease this transition, planning should begin in the teen years when the child is likely to have a more robust support system that includes the education system in addition to family, friends, and informal supports such as church and youth group relationships. Early transition planning can maximize those services that are still available. Planning should be person-centered with the goal of maximizing independence, life long functioning, and quality of life.

The Sonoran UCEDD has established a medical home at the UPH Hospital Family & Community Outpatient Clinic at Kino Campus for patients with developmental disabilities with an emphasis on this transition from pediatric to adult care. We provide comprehensive, continuous, family-centered, and integrated quality care. The medical home model developed in pediatrics and has been subsequently embraced by all major medical organizations as an effective way to provide preventive and holistic care with a focus on reducing hospitalizations and increasing quality of life. At the medical home we receive community referrals but also work with the Children’s Clinics to transition young adults out of pediatric care, coordinating health care alongside vocational, educational, and social services as needed.

To ensure that our medical home is family-centered, we are forming an advisory council comprised of patients, caregivers, and legal guardians. The work of the council will be to enhance the transition process and identify strategies to better serve patients with disabilities. Because transition can be a difficult and confusing process, families who have been through the medical transition process can benefit those newly entering the adult medical system by sharing their experiences. The advisory council will create a support group to facilitate this transfer of knowledge and information exchange.

For information about the medical home at UPH Hospital, please contact Stacey Hersch [shersch@email.arizona.edu; 520.400.6751]
Historically, people with developmental disabilities have been excluded from consideration for competitive employment. From worries about their safety and loss of benefits to outright discrimination – people with DD have often been relegated to staying at home or in sheltered or separate work settings regardless of their desire or ability to be employed. In Arizona as recently as 2008, only 20% or 1,571 persons with intellectual disabilities in the Arizona DD service system were served in integrated employment, while over 6,000 individuals participated in facility-based work or day programming.

There are real and perceived barriers to employment for young adults with DD graduating from high school. These may include:

- **Attitudinal barriers** – employers and co-workers who think people with DD can’t do the job and people with DD who believe they can’t work because that’s what they’ve been told.

- **Lack of adequate training and transition work experiences for youth with developmental disabilities** – leaving them unprepared and non-competitive in the workforce.

- **Concerns about loss of benefits and health care** – if the person with DD is on SSI and State Medicaid (AHCCCS), a job could mean the loss of necessary services.

- **Ignorance of resources to help with employment of individuals with DD** – both on the employer’s and potential employee’s part.

There are many resources in Arizona, including those provided by the Sonoran UCEDD, to address the real and perceived barriers to employment for transition age young adults. These resources help build an atmosphere where people with DD are judged on their merits when applying for a job and have the training and supports needed to be successful. Some of the current programs available include:

**Freedom to Work:**
AHCCCS offers health insurance for qualified individuals who are working and have a disability. The program is available to qualified working age Arizona residents with disabilities who receive Social Security or have been determined to be blind or disabled and has countable income, after allowable deductions, under $2257 per month. Individuals must pay a small premium for this health insurance coverage. [http://www.azahcccs.gov/applicants/categories/workingdisabled.aspx](http://www.azahcccs.gov/applicants/categories/workingdisabled.aspx).

**Project SEARCH:** A nationally recognized employment training program for youth and young adults with significant disabilities is known for its innovative practices and unique employer-driven model. Project SEARCH began at Cincinnati Children’s Hospital Medical Center in 1997 and has since been replicated in more than 31 states, totalling 140 sites within the US and abroad.

Interns experience total immersion in a business setting through a series
of rotations in various departments within a host business as well as instructional time for reinforcement of employment skills. Project SEARCH Arizona, an initiative led by the Sonoran UCEDD to replicate the model in Tucson and across the state, is a community partnership among the following organizations: Arizona Department of Economic Security, Division of Developmental Disabilities and Rehabilitation Services Administration; Pima County Joint Technical Education District; Blake/Easter Seals Foundation; Tucson Unified School District; Linkages Arizona; DIRECT Center for Independent Living; Arizona Developmental Disabilities Planning Council; and UA Healthcare.

UPH Hospital of UA Healthcare distinguished itself as the first Arizona site by launching a small pilot program serving six young adults in August 2009. The hospital now hosts two Project SEARCH programs: a Young Adult program for individuals between 18 - 26 years of age who have graduated from high school and a larger High School Transition program for students who are close to meeting graduation requirements. This program is administered in partnership with the Pima County Joint Technical Education District and serves students from 12 districts.

The UCEDD and the Arizona Developmental Disabilities Planning Council have been working with partners in Maricopa County to explore expansion opportunities in the Phoenix area and hope to develop sites in other areas of the state within the next few years. For more information contact Laura Schweers [schweers@email.arizona.edu; 520.626.0677] or go to http://projectsearch.sonoranucedd.fcm.arizona.edu.

"I love this program. Couldn’t be happier or more blessed. I like that I get to learn new stuff … a big adventure for me. I like preparing for a job." — Tawnie (left)

"My first rotation is in Sterile Processing where I get all surgical supplies ready on a cart and take them to the operating room … I always wanted to work in a hospital and this program gives me experience and training. It is a perfect fit for me." — Bianca (right)

Ticket to Work: The Ticket Program is part of the Ticket to Work and Work Incentives Improvement Act of 1999 – legislation designed to remove many of the barriers that previously influenced people’s decisions about going to work because of the concerns over losing health care coverage. The goal of the Ticket Program is to increase opportunities and choices for Social Security disability beneficiaries to obtain employment, vocational rehabilitation (VR), and other support services from public and private providers, employers, and other organizations. Under the Ticket Program, the Social Security Administration provides disability beneficiaries with a Ticket they may use to obtain the services and jobs they need from a new universe of organizations called Employment Networks (ENs). For more information: http://ssa.gov/work/

Linkages Arizona: Joins with employers and local rehabilitation agencies in an exciting partnership. Linkages currently serves Tucson, Casa Grande, Yuma and Maricopa Counties. Linkages maintains a job matching database where it serves as the liaison between area businesses with employment openings and participating rehabilitation providers with qualified people who have a disability and are ready to work. http://www.linkagesarizona.org/
“Where I am, in the radiology department, the area is open so I can see patients walk by. Because I have been in the hospital so much of my life because of my medical condition, I like being here to help people. I like learning new things. I like all of the tasks in my rotation, best of all is answering phones and faxing documents. I want to stay within the hospital and get training to find something permanent.”

— Danielle

**Vocational Rehabilitation (VR):** Helps individuals with disabilities prepare for, enter into, or retain employment through the provision of services such as skills assessment, vocational counseling, assistive aids or services, assistance in finding a job, modifications to the work environment, and tuition or other training related costs. For more information: [https://www.azdes.gov/RSA/](https://www.azdes.gov/RSA/)

**National Service Inclusion Project (NSIP) and Arizona Inclusion NOW:** Works to expand efforts to improve the recruitment and enrollment of persons with disabilities in national service (such as AmeriCorps, Vista, Learn and Serve, and Senior Corps). The Sonoran UCEDD has just received a grant from NSIP and AUCD for a project that will work with programs and individuals with disabilities in Southern Arizona to further the goals of the Arizona National Service Inclusion Work Team Strategic Plan.

The project uses a two-pronged approach targeted at increasing recruitment and participation of individuals with disabilities in national service programs:

1. Increasing awareness in the disability community about opportunities for national service.
2. Increasing service program knowledge and understanding of persons with disabilities as valued participants in national service.


**Erin Riehle, Project SEARCH Co-Founder, Visits Arizona**

Jim Click, Jr., one of Tucson’s most visible philanthropists, hosted a luncheon at the Westin La Paloma in early October with guest speaker Erin Riehle. Ms. Riehle presented the Project SEARCH model to leadership from Tucson area hospitals: Carondelet Health Network, Tucson Medical Center, UA Healthcare, Northwest Medical Center, and Oro Valley Hospital. In addition to raising awareness about Linkages, the non-profit employment agency founded by Mr. Click, the event served to engage the health care community around how Project SEARCH, through its innovative training approaches, can benefit their organization and to explore opportunities for collaboration with the program at UPH Hospital.

A business advisory council has since been established with representation from each hospital. The council’s initial effort will be to develop an employment referral network to assist with job placement of interns trained in the program. Other collaborative efforts could include program expansion to a second hospital, developing a mentorship program, and providing job shadowing opportunities for interns to give them experience with other hospital environments.

Mr. Click has been a strong proponent of Project SEARCH since partners first began the process of replicating the program in Arizona.

While attending the graduation ceremony honoring the first group of interns this past summer, he formulated the idea to reach out to other hospitals with the goal of enhancing job opportunities for graduates and also helping these organizations meet their hiring needs for trained and highly motivated employees.

**Erin Riehle, Project SEARCH Co-Founder, Visits Arizona**

Jim Click, Jr. at the Project SEARCH Intern Graduation, June 11, 2010
Person-Centered Planning (PCP) can be a very effective tool for transition planning. This guided approach helps an individual identify the steps needed to achieve their hopes and dreams through a process in which a person and their circle of support – family, friends, support providers – have an opportunity to determine what is important to the individual including likes, interests, preferences, needs, talents, and skills. The team looks at how the person would like their life to be in the future, and how to support the individual in achieving that goal.

In learning what is both important to and for a person, all engaged in the process can help develop a vision of the future which is aligned with what the person enjoys and wants out of life. Topics often addressed include further education, employment and training, living arrangements, community and social activities, and health care – issues that we all consider during transition into adult life.

Person-centered planning is simply a concrete way of organizing this universal process. Not only is a person-centered plan a working document that chronicles a person’s interest, relationships, and goals that inevitably changes over time, but it is also a foundational plan that can be used as an advocacy tool or information resource for other plans such as an IEP (Individualized Education Plan), especially during transition planning in high school.

Overall, person-centered planning and the resulting plan allows a person to demonstrate and articulate where they currently are, their vision of a happy future, and the necessary steps and supports needed to achieve that future – thus an effective transition tool.

The Division of Developmental Disabilities (DDD) and the Sonoran UCEDD administer the Southern Arizona Person-Centered Planning Model Program which targets youth who are 16 through 22 years of age, are eligible for DDD services, and are committed to participating in trainings and planning sessions with their families. Youth who participate in the program will be equipped with tools and experiences in leading and/or actively participating in their own person-centered planning process. For more information, please contact Jacy Bell [jkbell@email.

Planning for people with developmental disabilities too often narrowly focuses on what is important “for” individuals such as health and safety. Person-centered planning also looks at what is important “to” a person.

"It [person-centered planning] was an eye opener in so many profound ways, not the least of which was hearing strikingly simple yet deeply perceptive observations from the near and dear on our team who know and see Aileen from a more objective perch than ours. Although we don’t use the plan as a daily practical map at this point, and in fact may never do so, the process opened doors and windows that have let in light and life. And I know the plan is there, both as method and substance, to fall back upon when and if we find ourselves stuck.”

— Caroline, mom of Aileen, 2008

Note: Photos are from a Group Planning Session in Tucson, AZ
Across the nation people are interested in creating and enhancing opportunities for people with intellectual and other developmental disabilities to attend college. In some instances, projects, like the new one at the University of Arizona’s College of Education, partner with a local school district to assist students with disabilities as they transition to take part in a college experience. Project Focus (Focusing Opportunities with Community and University Support) will work with 50 high school students from Tucson Unified School District during the next five years, providing the planning and resources for a college transition experience. For more information, please call Dan Perino or Phyllis Brodsky [520-232-8430].

Other states, as part of the larger Think College initiative, a collaborative effort between seven UCEDDs and other national organizations and housed at the Institute for Community Inclusion (ICI) at the University of Massachusetts Boston, work with adults with intellectual and other developmental disabilities to attend college. Still others partner with colleges on making instruction and activities accessible to students of varying abilities.

To find out more about what is happening nationally and to explore options around postsecondary education, go to www.thinkcollege.net, a website that features numerous resources for families, professionals and students contemplating the transition to the world of college.

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**housing**

**Education Program Addresses Housing Needs**

Arizona is experiencing a diminishing developmental disability service landscape including lack of housing supports for families while at the same time Arizona families do not always have the knowledge or skills to successfully access or create community living situations.

Community Inclusion Now, a new program designed and administered by the Sonoran UCEDD and supported by grant funds from the Developmental Disabilities Planning Council (DDPC), addresses the important issue of how to give families the information they need to create affordable and accessible community living situations for themselves and their family members with developmental disabilities.

Beginning October 1st and running through June 30th, 2011, Community Inclusion Now, under the direction of Lynne Tomasa, PhD, will deliver six educational sessions aimed at providing training on a diverse range of topics addressing needs around housing – everything from knowing what services and supports are available to future planning and home buying.

The six educational training sessions include:

- **Community Services and Supports: What We Have and What We Need.**
- **Transitions: My Chosen Life and What It Means to Me**
- **Consumer Controlled Housing:**

Making Informed Choices In Rental and Home Ownership
- **Shared Living: Important Discussions about Daily Life**
- **Special Needs Planning: Guardianship and Living Trusts**
- **Financial Education and Planning**

Each of the two-hour sessions will be delivered from Tucson to additional communities across the state via videoconferencing (Arizona Telemedicine). The sessions will begin in December and continue monthly through May 2011.

For more information, contact Lynne Tomasa [ltomasa@email.arizona.edu; 520-626-7823].

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Thanks to your generous support, we continue to ensure that equal opportunities and a quality of life are accessible to all persons with developmental disabilities.

If you would like to learn more about making a tax-deductible gift to one of these vital programs, please contact Thom Melendez, Director of Development, at 520-626-4961 or by email at tmelende@email.arizona.edu.
The Sonoran UCEDD Interdisciplinary Training Program prepares students from a variety of disciplines to become leaders and advocates in the disability field with an understanding of the principles of self-determination and meaningful community inclusion for all people with disabilities.

In addition to my PhD studies in Special Education, I am working with pediatricians to create a medical home in Douglas, AZ. My training at the Sonoran UCEDD has provided me the opportunity to network and collaborate with other professionals from a variety of disciplines.

As part of my graduate studies (MPH/MBA), I have an internship with the UCEDD Border Initiative wheelchair project in Nogales, Mexico. This opportunity allows me to combine my skills in business and public health as I work with my Mexican colleagues to create a marketing plan to make the wheelchair shop sustainable and wheelchairs more accessible. It is inspiring to be a part of a project that can provide highly skilled employment opportunities to wheelchair users as well as helping to meet the demand for providing appropriate customized chairs in northern Mexico to people of all economic means. As a UCEDD trainee I am learning more about the context that surrounds this project.

In addition to my graduate work in special education, I have appreciated how the UCEDD seminar series has expanded my understanding of social issues related to disability. With this understanding, I have been reviewing the literature for approaches to building a collaborative evaluation method that could be used to explore connections between vocational education, employment outcomes, and the broad personal aspirations of individuals with intellectual disabilities.

I am a doctoral student in the UA’s Center for the Study of Higher Education on the research track. I intend to focus my investigations primarily on student-related issues. To date, I have studied the college-going experience of students of color, the resilient nature of African-American and Latino students, and the influence of spirituality on students’ academic and professional aspirations. My training at Sonoran UCEDD has provided me with a broader knowledge of issues affecting those with developmental disabilities, which enables me to more critically analyze and interpret the experiences of students with disabilities.

I am a second year medical student at the University of Arizona. I joined the UCEDD trainee program as an individual whose life has been incredibly enriched by working with individuals with disability. As a trainee, our graduate education is enhanced by the programs’ seminars which elucidate disability through a sociopolitical lens. The program fuels an existing passion for disability advocacy and provides the knowledge and tools to enable me to become a better proponent for my future patients.

To learn more about the program, visit http://sucedd.fcm.arizona.edu/trainee_program.
Building a Research Agenda for the Inclusion of People with Disabilities in End of Life Decisions: The Literature Identifies Key Issues

UCEDD staff Lynne Tomasa and Alberto Guzman, along with Jessica Post (trainee) and Carol Howe (medical librarian/geriatrician) reviewed the literature on end of life care for persons with developmental disabilities and found it to include a broad range of important issues.

The team focused their review on the ethical issues regarding consent and decision making in order to 1) assist people with disabilities and those who support them to plan and engage in practices that facilitate communication and inclusion, and 2) to identify training needs and gaps in the research. The review process included articles from 1992 to present that were discovered through searches of multiple databases across disciplines, related article searches, book reviews, and articles posted on related websites. A total of 42 articles on ethical issues and decision-making appeared in disability, medical, hospice and palliative care, legal, religion, and policy journals.

The themes that emerged included clear communication of terminal diagnosis; inclusion in decision-making about treatment or no treatment; determination of individual’s decision making capacity and comprehension; need for staff training; treatment decisions by health care providers based on disability and incorrect assumptions; consent issues; and concepts of quality of life. Additional studies that pay close attention to research design, data collection methods, and privacy and consent issues are needed.

You can review the 2010 AUCD conference poster submission at http://sonoranucedd.fcm.arizona.edu/sites/sonoranucedd.fcm.arizona.edu/files/BuildingResearchAgenda_AUCDposter.pdf.

The Association of University Centers on Disabilities (AUCD) is the membership organization that supports and promotes the network of interdisciplinary centers, like the Sonoran UCEDD, advancing policy and practice for and with individuals with developmental and other disabilities, their families, and communities.

At the annual AUCD conference this November, Leslie Cohen, Sonoran UCEDD Director, was elected Treasurer of the Board of Directors. Congratulations to Leslie! For more information about AUCD and the national network, go to http://www.aucd.org/template/index.cfm.
ArtWorks Celebrates the Opening of the Mary T. Paulin Gallery

On September 24th, the community joined the staff and artists of ArtWorks to celebrate the opening of its new gallery in honor and appreciation of longtime supporter Mary T. Paulin. The gallery occupies a room in one of its casitas and showcases works from many of the artists at ArtWorks, a day program and art studio for adults with developmental disabilities.

Directed by Jeanne Carrigan, PhD, ArtWorks is housed with the Sonoran UCEDD. It provides 20 adults, ages 22 to 70 with primarily intellectual disabilities and autism, an opportunity to develop their artistic potential while learning social skills, self-care and independence in a culturally-diverse setting.

Holiday Arts Show
Artwork display & dessert!
December 16th, 7:00pm – 9:00pm
Jewish Community Center
3800 East River Road, Tucson

Featured Artists
James W. Weed
Chris Ortiz
Jessica Leavenworth

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The Sonoran UCEDD produces a variety of publications, including Sonoran UCEDD News, that communicate the ways we are connected to individuals and activities in Arizona and across the country.

If you would like to be added to our mailing list, please send an e-mail to ucedd@email.arizona.edu and type your name in the subject line or call 520-626-0442.

Current and archived issues of the newsletter can be accessed at http://sonoranucedd.fcm.arizona.edu/newsletter.

To receive this document in an alternate format, please call the Sonoran UCEDD at 520-626-0442.