



*A University Center for Excellence in
Disabilities Education, Research and Service*

When Barbara Romain was diagnosed with a retinal degenerative disease in 1984, she'd been painting in oils for several years. She says, "As I became legally blind, I seriously questioned my ability to continue painting. I slowly transformed my thinking and techniques to incorporate my physical limitation as an integral part of my work. As a result, I am continually exploring the boundaries of taste and perception, asking what does a painting need to look like? Physical movements of my body must replace the precision of my eyes as the vehicle for placing marks. Improvisation in the moment has been inspired by collaborations with experimental theater artists, jazz musicians, and poets.



The National Arts and Disability Center (NADC) at Tarjan is about creating opportunities for artists such as Barbara to continue their professional development. As part of its California Arts and Technical Assistance grants program, the NADC funded her to attend the VSA Arts International exhibit. She has since been selected as a Teaching Artist for VSA and is grateful to the NADC and the California Arts Council for their support.

“The Tarjan Center is about taking clinical expertise and extending out to the disability community. The Tarjan Center gives the interns a broader view of the disability world, from an interdisciplinary viewpoint – not simply a focus on the physical issue.”

*Eileen Fowler, PhD, PT, Director of Research and Education,
UCLA/Orthopaedic Hospital Center for Cerebral Palsy and Tarjan Center*

The strength of a society springs directly from its ability to realize and engage the unique potential of each individual. A truly healthy community supports the unlimited possibilities in all its members.

The Tarjan Center at UCLA supports possibilities across the lifespan in a variety of ways.

- Our clinical services help individuals with disabilities better their quality of life.
- Our resource center and education forums empower individuals with disabilities and their families.
- Our training programs prepare professionals to better respond to the needs of people with disabilities.
- Our arts and volunteerism initiatives mobilize the community to engage people with disabilities, widen opportunities and change attitudes.
- Our research develops new knowledge that ultimately increases the capacity of people with disabilities to lead satisfying lives across the lifespan.
- Our information sharing disseminates disability-related information and research findings to the broad community of individuals, families, professionals and policymakers.
- Our advocacy and policy recommendations foster systems transformation and address barriers that stand in the way of self-determination.

“We have a wonderful opportunity to provide education to students, health care professionals, parents and other caregivers to benefit individuals with disabilities of all ages.”

Joan Earle Hahn, Assistant Adjunct Professor, UCLA/School of Nursing and Tarjan Center



National service is one of our country's greatest vehicles for social change, linking citizens to local community improvement efforts through programs like Americorps.

Oscar Reyes, project director of the UECC Americorps program at the University of California, Riverside (UCR), happened to meet Tarjan's Director of the Alliance for Inclusion Advancement, Karen Leventhal, through an Americorps Alumni event. It seems that both had been part of this national domestic volunteer program, although at different times.

It was a fortuitous encounter.

The Americorps volunteer group at UCR tutors at local elementary, middle and high schools and also helps with community beautification programs, such as graffiti removal. Oscar was looking to recruit students from across the campus to participate, and he was especially interested in opening the program to those with disabilities.

Enter the Tarjan Center, which helped to facilitate a meeting between him and the UCR Student Special Services Office. That, in turn, led to the office running an ad in the Special Services newsletter, which led to increased student awareness and interest. Oscar hopes to engage some students with disabilities to volunteer this spring.

"The Tarjan Center was very helpful in setting up our meeting and answering questions," Oscar notes. "And they continue to be available." "I'm glad I found the Tarjan Center," he enthuses. "It's a great resource."

As a result of this collaboration, students with disabilities at UCR will be able to enjoy the experience and satisfaction of volunteerism.

"University Centers of Excellence have a role in providing direct service and making others aware of the special needs and circumstances of those with developmental disabilities, but our main mandate is to advocate at the program level, facilitate the sharing of knowledge, and effect systems change. Our goal is to really improve the lives of individuals with disabilities."

Andrew Russell, MD, Co-Director, Tarjan Center

A University Center for Excellence in Disabilities Education, Research and Service

The Tarjan Center is part of a national network of federally designated University Centers for Excellence in Developmental Disabilities (UCEDDs).

University Centers for Excellence were first authorized by President John F. Kennedy in 1963. Their purpose is to promote independence, productivity, and full inclusion of people with developmental disabilities in their communities. Today, there are 64 UCEDDs with at least one in every state and territory in the United States.

Founded in 1969, the Tarjan Center is unique in the national network. It is the only program based within a Department of Psychiatry (the Jane & Terry Semel Institute for Neuroscience and Human Behavior). Our founder, Dr. George Tarjan, was an internationally-recognized expert in the field of developmental disabilities who pioneered clinical services, the training of personnel, and the establishment of a research center dedicated to the field of mental retardation.

Today, the Tarjan Center is a bridge connecting the knowledge, expertise and resources of the university to persons with disabilities and the service delivery systems of the community. Our mission is to provide leadership in education, research and innovative practices to support the quality of life and inclusion of all people with disabilities and their families. We do this through:

- University Education
- Community Services
- Technical Assistance and Program Evaluation
- Research and Demonstration of Exemplary Programs
- Information Dissemination
- Ensuring the Participation of People with Disabilities in Our Work

Our faculty and staff represent a variety of academic and research disciplines, but they share a common commitment to and interest in disabilities.

Our Core Program

The Tarjan Center accomplishes its mission across the lifespan through three overarching and interconnected core areas: Arts, Health & Well-Being, and Social & Civic Engagement.

“We’re really about social change, using training, research and information to effect overall change in the long run.”

Bethany Stark, MA, Parent Coordinator, Tarjan Center

Pamela Walker is a writer, arts administrator and performer with a disability – and spent the first part of her life hearing the words “No, you can’t.”

So she set out to make “Yes, I can,” a reality. Along the way, she connected with the National Arts and Disability Center (NADC). And that has made a big difference in her life.

Pamela first met NADC Director Olivia Raynor when both were speakers at an event about art and disability. That was more than 10 years ago, and since that time, Pam’s participated in many NADC events and worked as a consultant for the center. It has been a mutually beneficial relationship.

Over the years, she notes that the NADC has been “a valuable source of information and networking.” Her work on grant panels, for example, has allowed her to exchange ideas with people around the nation.

The NADC also gave her technical assistance in the form of an Arts and Accessibility mini-grant to acquire voice-activated software. That enabled her to write her book “Moving Over The Edge – Artists with Disabilities Take the Leap.” That, in turn, inspires other artists.



“The greatest impact of the NADC is not tangible, but in the validation of my role, my right to be an artist and acknowledgement that it’s a viable career choice,” she says. “I get taken seriously as an artist – that’s hard enough to achieve in general, but worse when you have a disability.”

“Without the NADC,” she continues, “I wouldn’t have been able to connect with the number of people I have.”

That’s the Tarjan idea – connect people and watch those connections make a difference.

We help bridge the gap between research and practice in mental health for people with developmental disabilities; create new opportunities for inclusion in the arts; and establish more effective partnerships with the community to improve the quality of life.”

Olivia Raynor, Co-Director Tarjan Center, Director National Arts and Disability Center

National Arts and Disability Center

The National Arts and Disability Center (NADC) at the Tarjan Center is the only one of its kind in the nation. It is a unique resource – an information and training center dedicated to the full inclusion of artists and audiences with disabilities in all facets of the arts. Through our Web site, we publish resource directories and training materials, as well as showcase the talent of individuals with disabilities.

Through the NADC, we help advance the professional development and employment of artists with disabilities. We also provide guidance and education to arts venues on how to remove barriers that prevent people with disabilities from taking part in the arts community.

In partnership with the National Endowment for the Arts and Very Special Arts (VSA), NADC administers The Statewide Forums on Careers in the Arts initiative, helping individual states establish partnerships between the state arts agencies, VSA arts affiliates, artists with disabilities and vocational, education, and rehabilitation professionals to advance employment in the arts. To date, 20 states have been supported involving thousands of participants.

Annually, the NADC partners with the State Council on Developmental Disabilities to hold an Art Poster Contest for artists with disabilities to draw attention to their talent and capabilities. Designs around themes such as “Hire Value,” “Believe and Achieve,” and “Yes, I Can” have resulted in hundreds of submissions depicting people with developmental disabilities actively involved in their communities. The posters are distributed throughout the state.

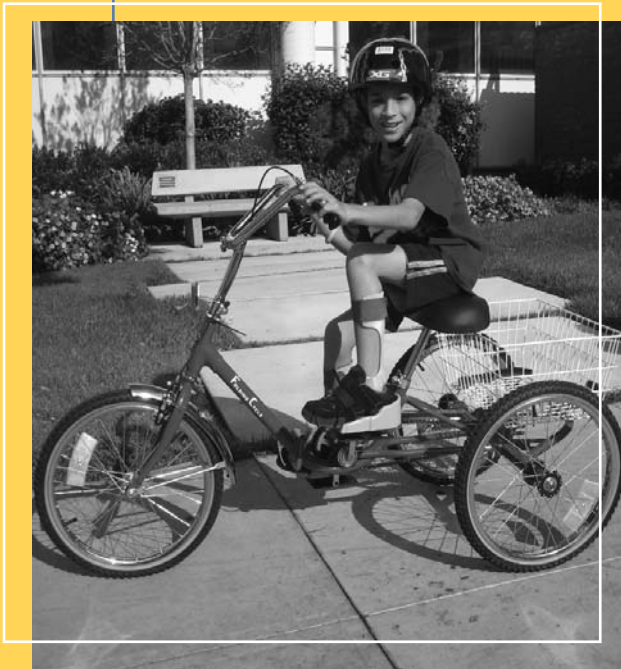
“As a pre-medical student, I began my work with the center hoping to gain more experience with patients. I have come to understand that a person with a disability may require medical attention, but that his or her psychological and social issues can run much deeper.... There is no doubt in my mind that my experiences will help me to become a more effective physician.”

Nader Khajehnajafi, UCLA Student

Kids on bikes are a universal image that calls to mind childhood fun.

But for children cerebral palsy the simple act of riding a bike can be major challenge. Children with cerebral palsy typically have muscle weakness and lower fitness than their non-disabled peers. Recent research indicates that strength can improve with exercise, and cycling is an exercise that focuses on leg strength and overall fitness.

Enter the PEDALS project (Pediatric Endurance And Limb Strengthening in Children with Cerebral Palsy) of the Tarjan Center in association with the UCLA/Orthopaedic Hospital Center for Cerebral Palsy, and the Department of Biokinesiology and Physical Therapy.



Funded by the Foundation for Physical Therapy, the joint UCLA/USC study is headed by Tarjan faculty member Dr. Eileen Fowler. The study's purpose is to investigate the effect of a stationary cycling intervention on strength and function.

Children age 7-18 years are randomly assigned to either a cycling or a non-cycling (control) group. Both groups receive two evaluation sessions consisting of strength testing, assessment of functional ability, and questionnaires to assess health-related quality of life. Children assigned to the intervention group also receive 30 sessions of a stationary cycling intervention from a physical therapist over a three-month period.

In conducting her study, Dr. Fowler has found that while children in the cycling group may improve limb strength and endurance during the course of the study, "The children in the control group do not have an opportunity to benefit, and those in the cycling group tend to gradually lose strength and fitness when the study is over."

To keep the kids cycling and extend the effects of her work beyond the actual research phase, she and her team did some fundraising to enable all the children enrolled in the study to get a free bike. This encourages them to keep cycling and provides them with an opportunity to participate in a fun recreational activity with friends and family.

"It's become a wonderful community outreach program," Dr. Fowler notes. "I never anticipated the emotional impact on the parents when they saw their child ride a bicycle for the very first time."

It's also a perfect example of the multi-faceted Tarjan Center in action.

Mental Health

Our mental health programs address the unique and often unmet mental health needs of individuals with disabilities, helping sustain and support them with skilled practitioners who can provide continuity of care. We recognize the shortage of mental health professionals with expertise in developmental disabilities, and through our training and continuing medical education programs address this need for increased cross-training. We disseminate findings from the latest research and clinical best practices in mental health to consumers and their families.

Clinical and Community-Based Services

We support clinics in autism, Down syndrome, early intervention, mental health for individuals with developmental disabilities, Prader-Willi Syndrome, Fetal Alcohol Syndrome, and Williams Syndrome. We also sponsor a motion analysis laboratory, and an interdisciplinary clinic focusing on the medical management of movement disorders in children and adults with cerebral palsy and related movement conditions.

Research

One of the Tarjan Center's greatest strengths is our research faculty who are extending the knowledge of human development in many areas related to disabilities.

Faculty interests range from the mental and physical health needs of persons with developmental disabilities, to the study of movement disorders due to developmental and genetic disabilities, to the impact of prenatal alcohol exposure, and outcomes of preventive health interventions.

Education

We are training the next generation of professionals in health care, education and other allied fields through a variety of programs, such as increasing awareness of newer medical treatments for cerebral palsy, developing a groundbreaking, integrated approach to education about Fetal Alcohol Exposure, and supporting and educating students in clinical internships.

Other initiatives are bringing the field of Disability Studies to undergraduate education at UCLA and Pathway, a post-secondary education program for students with intellectual disabilities at UCLA Extension.

Community Service and Volunteerism

The Tarjan Center Service Inclusion Project (TCSIP) – in partnership with agencies such as the California Service Corps, the Corporation for National and Community Service, and the National Service Inclusion Project – facilitates regional and state partnerships that encourage the inclusion of people with disabilities in service and volunteerism. TCSIP also provides technical assistance and training to service organizations.

The Alliance for Inclusion Advancement is a three-state collaborative (California, Florida and Hawaii) whose goal is to increase the number of youth, adults and veterans with disabilities in community service opportunities that address local needs. This innovative approach utilizes University Centers for Excellence in Developmental Disabilities, the Hands On Network and the field of national service as a team to equip volunteers with disabilities to take a greater role in their community.

The Spencer-Russell Mini-Grant program – named in memory of two leaders in the disability field – provides support to community efforts to engage people with disabilities in service. Nonprofit organizations such as national service and volunteer programs, disability organizations, educational institutions, state agencies, and faith-based entities are eligible to apply.

Conference, Training and Information Sharing

An important part of the Tarjan Center is to share and disseminate information. We accomplish this through trainings, conferences and special programs. We also focus on contributing to public policy change through program evaluation, demonstration projects and surveys. For example, we recently collaborated with the Screen Actors Guild to conduct the first national study of employment among performers with disabilities in the entertainment industry.

“The Tarjan Center provides an umbrella under which we can all function according to our interests. It’s a place where people who are interested in developmental disabilities come to share their experiences, train people and provide advocacy and evidence-based treatment. It’s both multidisciplinary and multifaceted.”

Mary O’Connor, PhD, Training Coordinator, Tarjan Center

The annual Margaret Jones Professional Conference and Family Forum provides an opportunity for professionals and families to learn about the most pressing issues related to the treatment of individuals with cerebral palsy.

In collaboration with Community Housing Resources, Inc. (CHRI), the Tarjan Center provides training for families, disability organizations, case workers and service providers on a variety of housing-related subjects, including government rental assistance and housing options for persons with developmental disabilities.

On the undergraduate level, we are helping develop a Disability Studies minor, integrating research and scholarship to critically examine disability in terms of social, political, economic and cultural factors that define impairment.

Tarjan Advisory Committee

The Tarjan Advisory Committee provides advice and assistance to the Center on program objectives, project development and suggestions for new initiatives. A key function of the Tarjan Center is to disseminate knowledge to the community in areas of mutual interest. In turn, we rely on feedback from the community to help inform our work. We are actively engaged with consumers and seek to identify and mentor potential leaders to participate on our Tarjan Advisory Committee. The Committee is composed of key stakeholders, including a majority of persons with disabilities, family members, representatives of community agencies, and our Federal partners.

Funding Sources

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