The Developmental Disabilities Institute

The Developmental Disabilities Institute (DDI) is Michigan’s University Center for Excellence in Developmental Disabilities. It is one of 61 UCEDDs throughout the 50 states and in U.S. possessions such as Guam and the U.S. Virgin Islands. DDI was established in 1983 at Wayne State University by the Federal Administration on Developmental Disabilities (ADD), U.S. Department of Health and Human Services. DDI is mandated by ADD to provide statewide services and programs designed to enhance the lives of persons with disabilities. DDI’s programs and services accomplish the following:

- provide education to individuals;
- assist community agencies and human service systems as they shift policies and procedures to support consumers in making choices and controlling their own lives;
- investigate processes and products through systematic qualitative and quantitative methods;
- conduct research; and
- produce and distribute products that inform and contribute new knowledge.

Through its project sites, the institute provides support statewide to more than 20,000 persons with disabilities annually. DDI collaborates with organizations in almost every Michigan county to develop innovative strategies for meeting the needs of diverse communities.

Our Mission . . .

is to contribute to the development of inclusive communities and quality of life of people with disabilities and their families through a culturally sensitive statewide program of interdisciplinary education, community support and services, research and dissemination of information.

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DDI’s Sharon Milberger is Clinical Director for Health Promotion for the Special Olympics in Michigan. In November 2004, she was in Salt Lake City for training on the Special Olympics’ International Healthy Athletes program. With DDI colleagues, she also conducted Health Promotion activities with more than 300 athletes and coaches at the Michigan Special Olympics Winter Games, providing education on nutrition and the importance of physical activity (right).
DDI begins a new five-year initiative: Family Support 360°

The Institute recently began a five-year commitment to develop and operate the Detroit Family Support 360° project (Grant # 90DN0182, Administration on Developmental Disabilities/HHS). Detroit 360° is a one-stop center that helps families obtain the supports and services they need to enhance their family’s health and well-being. Families are eligible if they meet the following criteria:

- They have a child under the age of 18 who has a developmental disability;
- They live in Detroit, and;
- They are in need of services.

Families who meet eligibility requirements and enroll are assigned a Family Support Navigator uniquely qualified to assist them in pursuing family support services. The navigators are culturally diverse parents who have children with disabilities.

Having been through the human service system themselves, navigators are better able to help. Project director Elizabeth Janks says, “they are knowledgeable about formalized support systems in Detroit and know how to develop natural supports” for families.

In addition to their assigned navigators, enrolled families also receive:

- An individualized family plan based on services and supports they want or need.
- Information and referrals to enhance their child’s health and development.
- Coordinated access to services.
- Increased participation in family support services.
- Opportunities for peer support and friendship.

Family Support 360° partners include:

- Arab Community Center for Economic and Social Services (ACCESS)
- The Arc, Detroit
- Child Care Coordinating Council of Detroit-Wayne County
- Children’s Special Health Care Services
- Children’s Hospital of Michigan
- Community Living Services, Inc.
- Detroit Public Schools
- Detroit-Wayne County Community Mental Health Agency
- Latino Family Services
- Michigan Developmental Disabilities Council
- Michigan Department of Human Services
- Michigan Protection & Advocacy Services, Inc.
- Parents, family members, & self-advocates
- Skillman Center for Children/WSU
- State & local legislative bodies
- Wayne County Regional Educational Services Agency (RESA)
Team approach helps build Family Support 360°

To plan for and implement Detroit Family Support 360°, five new employees were hired to complement the project team. Julia Hernandez, Claudette Cameron and Drucilla Daniels joined the institute as our first Family Support Navigators.

Megan George is a graduate student in Wayne State’s Department of Social Work. As a student assistant, she works on the project in a wide variety of roles.

Michael Bray (M.A.) joined the institute as a research assistant. In addition to managing the Family Support 360° data set, he develops materials and conducts training sessions for the project.

Family issues demonstrate need for support services

Tia is a 28-year-old mother of seven children, three of whom have disabilities. Six-year-old Naija has Attention Deficit Disorder with Hyperactivity, as does Arnold, who is four. Tia’s youngest son, Cecil, has chronic health problems resulting in multiple hospitalizations.

Tia’s day begins at 5:30 with bathing, dressing and feeding the children. Once the school-age children are off for the day, she spends her time at doctor appointments or therapies for the younger ones. Despite a strong desire to work, Tia has been unable to keep a steady job since Naija was born. Each of the people she found to serve as a baby-sitter has proven unreliable and ill-equipped for the job.

Tia and her family are typical of the families that Family Support 360° is expecting to support: families who need individualized support to navigate the human service system. To refer yourself or a family to the project, contact Angela Martin at (313) 577-9470.

This story is true. Names have been changed to protect the identities of the individuals herein described.
DDI Programs and Projects

The Developmental Disabilities Institute participates in a wide variety of federal, state and locally-funded projects.

Projects and Research Studies

Project CARE provides evaluation services, technical assistance and training in promising practices at Detroit-Wayne County Community Mental Health Agency.

Interdisciplinary Perspectives on Disabilities convenes faculty from diverse departments and disciplines for a lecture series on Disability Studies.

Health Promotion in Urban Children: SPARK (Sports, Physical Activity and Recreation for Kids) examines barriers to physical activity and fitness and provides training in a curriculum focused on urban children. Focus groups with parents and teachers in Detroit and Oak Park identified barriers to healthy life-styles and how to overcome these barriers by tailoring future programs.

With WSU’s Interdisciplinary Studies Department, the Online Degree Survey assesses the interests of students with disabilities regarding an online bachelor’s degree program.

The Parent Coalition evaluates a comprehensive training model for parents of children with disabilities around the state.

Implications of the Human Genome Project: The Potential for Health Insurance Discrimination examines policies and practices of Health Maintenance Organizations regarding genetic testing and services for individuals with genetic-related disabilities.

Demography of Inclusive Education examines the under-representation of students of color in special education promising practices.

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DDI director serves national, international organizations

DDI Director Barbara LeRoy fills various roles around the country, and the world. She is board secretary for the U.S. International Council on Disabilities (USICD). In addition, this year she was elected to serve as vice-chair of Rehabilitation International’s (RI) Education Commission.

USICD is the US representative to both RI and Disabled Persons International (DPI). The council is a two-way information conduit between this nation and the world. It works to bring together disability-oriented agencies with like-minded persons and organizations to promote and facilitate implementation of forward-looking policies at home and abroad.

The Rehab International commission actively promotes and advocates for access to quality education for children and youth with disabilities worldwide. Its multi-year plan specifically focuses on improving educational opportunities in developing countries.

The commission’s agenda includes:
• working with the UNESCO flagship efforts on disability rights in education
• working with the UNESCO flagship and the World Health Organization to facilitate identification and school entry of children with disabilities
• promoting professional activities on educational issues relevant to the rights of persons with disabilities
• working collaboratively on research in areas such as:
  • identifying those children with disabilities who are not being schooled, why this has occurred, and potential remedies
  • improving educational quality in low resource nations
  • discovering links between disability, poverty, and educational status
  • exploring transitions to post-secondary education and other positive outcomes
Staff member lands university research grant to support adolescent girls with hearing impairments

DDI’s Chelsea Vandenbusche landed a coveted WSU Undergraduate Research Grant in December 2004. The award will allow her to examine issues involving adolescent girls who are deaf or hard of hearing, related to self-advocacy.

The project’s aim is to empower these girls to learn and use strategies to reduce their risk for becoming the victims of violence and abuse. The project, entitled “Ending the Silence in Michigan,” will run through August 2005.

Chelsea Vandenbusche is a student assistant in the Developmental Disabilities Institute.

In collaboration with the Macomb Oakland Regional Center, the Independent Facilitation Training Project trains individuals on how to become independent facilitators in the person-centered planning process.

Global Education conducts a program titled “Cross-cultural perspectives on disabilities.” During the summer of 2004, students and instructors convened in France as part of WSU’s Study Abroad program.

Preventing Guardianship studies guardianship training in Michigan with regard to self-determination.

SIDS Awareness raises awareness of SIDS in African-American families in Detroit.

Families Advocating for Self-Determination Through Technology and Communication Supports (FAST CATS) provides families with information to support self-determination in their children with disabilities. Online, the project provides a chat room and message board, as well as archived video teleconferences on topics such as alternatives to guardianship and self-determination.
Training Programs and Events

The **Empowerment Education** project, funded by the Administration on Developmental Disabilities, trains direct support professionals in best practice strategies across the life span. More than 1,300 direct support professionals and consumers received training at 84 events statewide during 2004. Training topics include:

- Conflict Resolution
- Stress Management: It’s All About Awareness, Attitude and Action at Work
- Self-Determination: Our Right to Meaningful and Fulfilling Lives
- Person-Centered Planning: Valuing the Contributions of Direct Support Professionals
- Supporting Growth Through Opportunity and Choices
- Supporting People in Establishing Friendships and Making Community Connections
- Making the Transition A.S.A.P.: As Smooth As Possible
- Ten Successful and Assertive Steps for Working with Professionals
- Teaching Made Easy
- Self-Advocates and Direct Support Professionals Working in Partnership to Achieve Life’s Dreams
- Pathways to Leadership

**DDI Students**

303 students from the disciplines of:
- Education
- Genetics
- Pediatrics
- Psychology
- Special Education
- Occupational Therapy
- Social Work
- and others
received training related to developmental disabilities from DDI staff.

Early On: What it Can Do For You, Your Patients, and Families. Lectures for pediatric residents, allied health and pre-service professionals, and Wayne State University medical students at Children’s Hospital of Michigan.

**Microenterprise Training** in collaboration with MARO Employment and Training Association.

**Cross-cultural Perspectives on Disability: An Exchange Program at the Abbey** helps to develop cross-cultural perspectives on disability through an exchange program for university students at the Abbey of Pontlevoy in France.

**Community Support for People with Disabilities** (at Schoolcraft College). Students learn how supports provision can form the basis for administration and management of human service agencies.

**Families Advocating for Self-determination Through Communication and Technology Supports (FAST CATS)** informs and supports families to enhance their child’s self-determination using peer-to-peer learning experiences and multimedia channels such as video teleconferences and a web site. Project teleconference topics included:
- Self-Determination
- Alternatives to Guardianship
- Inclusion

DDI’s **Disability Film Series** aims to increase understanding of cross-cultural perspectives on disability, selecting films in which persons with disabilities and/or disability themes are central from different countries and cultures.

DDI’s **Graduate Certificate Program** is an interdisciplinary curriculum aimed at preparing individuals to assume leadership positions as service providers, policymakers, administrators or educators who are committed to the full community inclusion of persons with disabilities.
Through the Michigan State Police Violence Prevention Training program, DDI provides training to Michigan law enforcement officers on investigating and preventing abuse and sexual assault against older individuals and persons with disabilities.

**Person Centered Planning and Evidence-based Learning.** Presentation to Detroit-Wayne County Community Mental Health Agency.

**Enhancing the Skills of Professionals: Respecting and Supporting Culturally Diverse Families who have Children with Disabilities.** Family Support Minority Outreach Project Training to the Wayne County Interagency Coordinating Committee and Woodhaven-Brownstown Schools, Teach Our Tots Early (TOTE) Program.

**Established Conditions and Early On – Prematurity.** Lectures for Wayne County Early On Service Coordinators at Detroit Health Department.

**Inclusion and Natural Supports Training to consumers.**

**Outcomes for Children with Mild and Unilateral Hearing Impairment.** Bridges to Literacy presentation to Wayne State University Audiology/Speech Language Pathology faculty.

**Person Centered Planning and Independent Facilitation.** Training for staff at Blue Water Centers for Independent Living.

**Fetal Alcohol Syndrome.** Grand rounds lecture for medical staff and allied health professionals at Children’s Hospital of Michigan.

**Crisis Intervention in the Hospital Emergency Room for Children and Adolescents.** Presentation to Project Care and agency staff at Detroit-Wayne County Community Mental Health Agency.

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**DDI’s Milberger to lead gifted education alliance**

Sharon Milberger serves as a board member and is president-elect for the Michigan Alliance for Gifted Education. The alliance provides leadership, advocacy, and support of differentiated education and services for meeting the unique needs of gifted, talented, and creative students statewide.

As president, Milberger plans on working to increase awareness about “twice exceptional” children. These children are simultaneously gifted and have special needs such as a learning disability, ADD/ADHD, Asperger Syndrome, etc.

Twice exceptional children often have a hard time in our education system. Since their giftedness can hide their special needs—and their special needs their giftedness—they are often labeled as “lazy, unmotivated, or not trying.”

Many don’t even realize that a child can be both gifted and have a learning disability. “Ideally,” says Milberger, “increased awareness will result in identifying and meeting the needs of twice exceptional children.”

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**Dissemination**

**Central Conference of University Training Programs in Developmental Disabilities Media Exchange.** Topics included:

- Young Children with Mental Health Issues
- Zero Tolerance in Schools: The Dilemma of Children’s Mental Health Issues
- Children and Violence: Diagnostic and Treatment Issues
- Children with Mental Health Issues and their Families: Supports and Resources
Publications and Resources developed by DDI staff


Janks, E. (2005) Expanding Job Opportunities for Direct Support Professionals: Is this job the right one for you?


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Director’s research leads to new book

DDI Director Barbara LeRoy wondered what women with developmental disabilities experience as they age — and what service providers and researchers can learn from them. This focus led her to co-author (with Patricia Noonan Walsh) Women with Disabilities Aging Well: A Global View.

The book weaves informative research with the oral histories of more than 160 women in 18 countries. The authors’ research and the personal stories they collected explore factors contributing to healthy aging. They also suggest how professionals can help women with disabilities live lives of dignity, respect, and community participation. In the book, we discover how women with disabilities around the world manage everyday issues such as:

- economic factors (securing employment, gaining economic control, and financing living arrangements)
- personal issues such as grooming, mobility, and support systems
- health and nutrition
- recreation
- relationships with family members and friends
- overall well being and quality of life
- disability policies and programs that influence all these factors

Readers will have the cross-cultural perspective and research-based facts they need to help ensure healthy aging for women with disabilities and guide future research and policy.


**DDI’s LeRoy participates in second World Bank disability conference**

Director Barbara LeRoy (front left in photo at right) joined in the World Bank’s second international disability and development conference, “Disability and Inclusive Development: Sharing, Learning and Building Alliances.” About 600 participants, many with disabilities, joined panel discussions and sessions covering topics such as inclusive education, access to health care, employment, transportation and urban infrastructure, legal issues and others.

World Bank research shows that disability affects countries in different ways. In Uganda, households headed by a person with a disability are 38 percent more likely to be poor while in Serbia, the poverty rate of disabled people is 70 percent. In Honduras, people with disabilities have an illiteracy rate of 51 percent compared to 19 percent for the general population. In the U.S., there is almost a 70 percent rate of unemployment among disabled people. And in some parts of the world, as many as 80 percent of disabled children die before the age of 5, even in areas where the overall child mortality rate has been brought below 20 percent.
State, National and International Presentations


B. LeRoy & P.N. Walsh (June 2004). Life experiences of older women with intellectual disabilities. World Congress of Rehabilitation International. Oslo, Norway.


A. Martin (June 2004). An Introduction to Inclusive Education. Wayne State University College of Education. Detroit, Mich.


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The Graduate Certificate in Disabilities prepares students to assume leadership positions as service providers, policy makers, administrators or educators. Students learn to plan creatively and to implement activities that positively affect the lives of persons with disabilities.

This year, the Certificate Program was streamlined. Its new coordinator, Susan Adam Rita, seeks to provide educational opportunities to a new generation of graduate students.

The program’s interdisciplinary core insures that students connect with scholars from a wide variety of fields other than their own. Its urban focus means that they concentrate on real world problems with real world solutions.

To receive a brochure or for additional information, please contact Susan Adam Rita via e-mail at <av2438@wayne.edu> or at (313) 577-0333.
DDI began two series on disability issues during 2004.

In October, the institute began presenting monthly “Interdisciplinary Perspectives on Disabilities.” The lunchtime series highlights ongoing research at Wayne State. Speakers to date have included DDI director Barbara LeRoy on “Women with disabilities aging well,” DDI Associate Director for Research Sharon Milberger on “Domestic violence against women with physical disabilities” and David Moss on “Defining disability to combat stigma.”

In March, DDI presents the first in a series of author events. Rachel Simon, author of the award-winning book “Riding the Bus with my Sister” speaks at a free and open event. This occasional series spotlights authors who write disability-themed books for a general audience.

For information on either of these series, contact Kirsti Reeve by phone at (313) 577-8562, or e-mail her at <kreeve@wayne.edu>.

During the summer of 2004 the institute offered a three-week study abroad course targeted toward students with disabilities and/or students interested in the disability field. The program was held in a 1,000-year old abbey in the Loire Valley of France.

Working in collaboration with the Department of Interdisciplinary Studies (College of Urban, Labor and Metropolitan Affairs) and WSU’s study abroad program, the course was developed to use field trips, popular films and interactions with French college students with disabilities. In this manner, the course sought to expand its students’ cross-cultural perceptions of disability.

This summer, DDI will make a similar academic adventure available. Through a collaborative effort with WSU’s College of Education, the expanded 2005 program offers even more classes. This year in Madrid, students will have the opportunity to engage in the study of disability issues from an international perspective. Educators, psychologists, human service personnel and other professionals interested in providing service to diverse groups of individuals will have a chance to learn about disabilities and multiculturalism from an interdisciplinary, cross-cultural perspective.

To learn about DDI’s study abroad activities, please visit the program site on the World Wide Web at <http://studyabroad.wayne.edu/programs/05_spain.htm> or contact Sharon Milberger at <smilberg@math.wayne.edu>.

Studying last summer at a 1,000-year-old abbey in southern France (lower left), DDI students had an opportunity to visit the historic Chateau de Chenonceau and its environs.
Staff Professional and Community Service

Barbara LeRoy, Ph.D.
Advisor
- Rehabilitation Counseling Program, Michigan State University
- BEAM (Bringing the Eden Alternative to Michigan), Lansing
- Center and Institute Council – Office of the Vice President for Research, WSU
- Skillman Center for Children and Everyone Together, Inclusive Education Project
- Rehabilitation Counseling Program, WSU
- Early On Collaborative, Children's Hospital of Michigan

Member
- Children's Research Initiative, Office of the Vice President for Research, WSU
- AUCD Legislative Affairs Committee
- Statewide Education Coalition
- Special Interest Research Group on Aging and Intellectual Disabilities, World Health Organization

Governor's Appointee
Michigan Developmental Disabilities Council

Panel Reviewer
U.S. Department of Education, Office of Special Education Programs

Board Member
- American Association on Mental Retardation, Michigan Chapter
- Association for Community Advocacy (Ann Arbor)
- Arcadia Institute (Kalamazoo)
- United States International Council on Disabilities

U.S. Delegate
Education Commission, Rehabilitation International

Terry DeRocher Lerma, Ph.D.
Chair
- American Psychological Association Committee on Disability Issues in Psychology
- Michigan Developmental Disabilities Council Workgroup on Cultural Competence

Secretary
Board of Directors, Urban Caring Institute

Proposal Reviewer
American Psychological Association Convention, Society for the Psychological Study of Ethnic Minority Issues

Reviewer
Michigan Developmental Disabilities Council RICC Mini-grant Program

Community Reviewer
National Institute for Mental Health

Member
- Southeastern Michigan HIV/AIDS Council
- Centers for Disease Control Standing Panel

Angela Martin, M.S.W.
Board Member
American Association on Mental Retardation, Michigan Chapter

Facilitator
People First of Oakland County

Member
- Oakland County Regional Interagency Coordinating Council
- Wayne County Regional Interagency Coordinating Council
- The Arc of Livingston County Advisory Committee
- The Arc of Oakland County
- National Association of Social Workers
- American Association on Mental Retardation
- Association of University Centers on Disabilities National Consumer Council
- The Association for Persons with Severe Handicaps (TASH)
- The Howell Group
- Michigan Olmstead Coalition

Susan Adam Rita
Member
American Counseling Association

Donna M. Johnson
Member
- Michigan Association for Evaluation and Research Association
- Mid-Western Evaluation and Research Association

Michael Bray, M.A.
Member
- American Psychological Society
- Michigan Alliance of Direct Support Professionals
- National Alliance of Direct Support Professionals

Nathaniel Israel
Member
- American Psychological Association
- Society for Community Research and Action
- Division on Mental Retardation and Developmental Disability
- Society for Prevention Research
- Society for Research on Adolescence

Katherine A. Dukhan
Member
- Society for Applied Anthropology
- The Howell Group
- Aging and Developmental Disabilities Coalition

Megan George
Member
- National Association of Social Workers

Noel Kulik
Member
- The Association for Persons with Severe Handicaps (TASH)
- American Sociological Association

Kirsti Reeve, Ph.D.
Member
- American Association on Mental Retardation
- The Association for Persons with Severe Handicaps (TASH)
- Michigan Speech and Hearing Association
- Royal College of Speech and Language Therapists (UK)

Sharon Milberger, Sc.D.
Associate Professor (FTA)
Wayne State University
School of Medicine, Department of Community Medicine

Adjunct Assistant Professor
Wayne State University
Department of Psychiatry and Behavioral Neurosciences

Clinical Director for Health Promotion
Michigan Special Olympics

Board Member, President-Elect
Michigan Alliance for Gifted Education

Member
- The Michigan Adolescent and Adult ADD Network
- American Public Health Association
- American Association on Health and Disability
- Southeast Michigan Census Council
- Supporting the Emotional Needs of the Gifted
- Society for Epidemiologic Research Volunteer
- Jewish Federation of Metropolitan Detroit, Research Committee
- Jewish Federation of Metropolitan Detroit, Community Services Division

Elizabeth Janks, M.S.W., A.C.S.W.
President
Farmington Education Connection

Member
- National Association of Social Workers
- Michigan Direct Care Workforce Initiative Task Force
- Michigan Medicaid Long Term Care Task Force
- The Association for Persons with Severe Handicaps (TASH)
- The Howell Group
- University Centers of Excellence National Consumer Council
- Children’s Hospital of Michigan Skillman Early On Advisory Council
- Arc Michigan
- Wayne County Inter-Agency Coordinating Council
- Wayne County Chapter Board of Directors, CHADD (Children & Adults with Attention Deficit Disorder)
- Wayne County Head Start Advisory Council

Chelsea Vandenbusche
Member
- Phi Beta Delta International Honor Society
2004 Community Advisory Council

Sally Burton-Hoyle – Autism Society of Michigan
Vendella Collins – Michigan Developmental Disabilities Council
Jack Dobrecki – Self-advocate
Arlene Gorelick – Epilepsy Foundation of Michigan
Dohn Hoyle – Association for Community Advocacy
Chuck Jenkins – Parent
Radwan Khoury – Arab-American and Chaldean Social Radwan Services Council
LuAnn Loy – Partners in Policymaking
Larry Maniaci – Wayne County Residential Association, Homes of Opportunity
Dennis McDougal – Self-advocate
Mark McWilliams – Michigan Protection and Advocacy Services, Inc.
Deborah Patterson – Self-advocate
Linda Potter – United Cerebral Palsy Association of Michigan
Jane Reagan – Michigan Department of Education-Office of Special Education and Early Intervention Services
Rosanne Renauer – Michigan Department of Career Development - Michigan Rehabilitation Services
Robin Sefton – Self-advocate
Verna Spayth – ADAPT/Michigan
Sheila Starks – Self-advocate
Robert Stein – Michigan Assisted Living Association
Mark Weeks – Freedom Work Opportunities, Inc.
Pamela Hall – Office of Services to the Aging
Vanessa Winborne – Department of Education Comprehensive Program for Health & Early On Child Care

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