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24th Annual Conference on Medical Care  
May 31, 2013  
Space is limited - register today!  
Exhibiting Opportunities Available



Mainstreaming Medical Care  
985 Livingston Avenue  
North Brunswick, NJ 08902-1843



**24th Annual Conference**  
**On Medical Care for Persons With**  
**Developmental Disabilities**  
*Promoting Quality Healthcare*



**Friday, May 31, 2013**

**Westin Princeton**

**Forrestal Village • Princeton, New Jersey**

**Sponsored by:**

**Mainstreaming Medical Care**  
(A program of The Arc of New Jersey)

**In cooperation with:**

**The NJ Division of Developmental Disabilities**  
**The NJ Division of Medical**  
**Assistance and Health Services**

**With Educational Grants from:**  
**AMERIGROUP Community Care**

**Healthfirst NJ**

**Horizon NJ Health**

**PerformCare**

**United Healthcare Community Plan**

# Conference Schedule

**8:00 – 8:45**

**Registration, Continental Breakfast and Exhibits**

**8:45 – 9:00**

**Welcome and Opening Remarks**

**Walter Bender**, President, The Arc of New Jersey

**Thomas Baffuto**, Executive Director, The Arc of New Jersey

**Leone Murphy, RN, MS, CS**, Chair, Mainstreaming Medical Care Advisory Board

**Beverly Roberts, M.Ed.**, Director, Mainstreaming Medical Care Program, The Arc of New Jersey

## Plenary Session 9:00 - 11:00

**9:00 – 9:15**

**Introductory Remarks**

**Jennifer Velez, Esq.**, Commissioner, New Jersey Department of Human Services

## Morning Keynote Address 9:15 - 10:15

***When Do Aggression and Self-Injury among Persons with Developmental Disabilities Become Symptoms of Mental Disorders?***

**L. Jarrett Barnhill, MD, DFAPA, FAACAP**

Dr. Barnhill specializes in the diagnosis and pharmacological treatment of persons with developmental disabilities who have co-occurring psychiatric problems. He is a Professor and Director of the Developmental Neuropsychopharmacology Clinic in the Department of Psychiatry at the University of North Carolina at Chapel Hill, School of Medicine.

In providing services to individuals with intellectual and developmental disabilities, the boundary between challenging behaviors, aggression and self-injurious behavior (SIB) as symptoms of mental disorders is a complex one. This keynote presentation will explore that boundary and investigate biopsychosocial factors associated with episodic increases in these target symptoms. Case examples will be used to investigate these issues and apply this data to the process of differential diagnosis and treatment planning.

**10:15 - 10:35**

**Update On NJ Medicaid**

**Valerie J. Harr MA**, Director, NJ Division of Medical Assistance and Health Services, Department of Human Services

**10:35 - 11:00**

**Update On The Children's System of Care**

**Jeffrey J. Guenzel, MA, LPC**, Deputy Commissioner, NJ Department of Children and Families

**Break: 11:00 – 11:15**

## Morning Workshops 11:15 - 12:15

### 1. ***Practice Without Pressure: A New Model of Dental, Medical and Personal Care for People with Disabilities***

**Speaker: Deborah A. Jastrebski**, Founder & CEO of Practice Without Pressure, Inc., Newark, Delaware, 2011 Robert Wood Johnson Foundation Community Health Leader.

Practice Without Pressure (PWP) is a non-profit with a unique approach to training and routine treatment for people of all ages

with disabilities. This session will provide an overview through case histories to show the many benefits of PWP's holistic approach for both families, caregivers and professionals who support them. This session will also include PWP's Oral Health in the Home training program to improve daily oral hygiene for people with disabilities.

### 2. ***Mental Health First Aid for Consumers, Families and Staff*** **Speaker: Lucille Esralew, Ph.D.**, Clinical Administrator, Statewide Clinical Consultation and Training (SCCAT) and Statewide Clinical Outreach Program for the Elderly (S-COPE), Trinitas Regional Medical Center.

This workshop will explore ways to support persons with developmental disabilities, staff and families in the immediate aftermath of natural and manmade disasters, emergency relocations and conditions of extreme stress.

### 3. ***Ethical Challenges in Medical Decision-Making for Persons with Developmental Disabilities***

**Speaker: Jeanne Kerwin, D.MH**, Co-Chair, Ethics Committee, Coordinator, Palliative Care Team, Overlook Medical Center.

This session will examine some of the most common ethical challenges involving medical decision-making for persons with developmental disabilities, including Do Not Resuscitate Orders, Do Not Intubate orders, withholding and withdrawing of life-sustaining treatments, hospitalizations, and advocating for appropriate medical care while planning for good end-of-life care. Additional challenges will be discussed including how to initiate advance care planning for persons with cognitive impairments, how to deal with Danielle's law for those nearing the end of life and how to balance the burdens of continued medical interventions against the benefits that improve the quality of life for the person. Case examples will be provided to illustrate ethical issues.

### 4. ***Integrating Wellness and Fitness Solutions into the I/DD Community***

**Speakers: Evan Carlson**, Program Director, and **Joseph Galasso, PsyD**, Clinical Psychologist, VOLT Wellness, Glen Rock, NJ.

Wellness and fitness skills can promote the productive use of leisure time, inclusion in family activities, expansion of employment opportunities, and increased independence. The speakers will discuss VOLT Wellness' novel approach to therapy and how staff use fitness as a vehicle to provide clinical services. This workshop will help families and professionals identify and maximize meaningful participation in community wellness programs.

### 5. ***Wheelchair Transportation Safety: Striving Towards "Equal Protection"***

**Speaker: John Reck, PT, MPT**, Director of Assistive Technology, Matheny Medical and Educational Center, APTA Pediatric Certified Specialist (PCS) and RESNA Certified Assistive Technology Professional (ATP).

The purpose of this presentation is to educate all providers on current best practices in wheelchair transportation safety and raise awareness of the challenges and dilemmas wheelchair transportation providers face on a daily basis. The challenge of providing safe wheelchair transportation services in an organization requires a strong trans-disciplinary team process which includes healthcare professionals, transportation drivers, educational staff, rehabilitation engineers and suppliers, caregivers, families and individual wheelchair users.

**Lunch: 12:15 – 1:15**

## Plenary Session 1:15 - 2:15

1:15 - 1:30

**Overview of NJ's plans for the Administrative Services Organization – Managed Behavioral Health Organization (ASO/MBHO), and the provision of behavioral health services for persons with I/DD**

**Lynn Kovich, M.Ed.**, Assistant Commissioner, NJ Division of Mental Health and Addiction Services

## Afternoon Keynote Address 1:30 - 2:15

### *Weight Loss Findings and Success Stories for Persons with Developmental Disabilities*

**Richard R. Saunders, Ph.D.** Professor Saunders is a Senior Scientist Emeritus in the Schiefelbusch Institute for Life Span Studies at the University of Kansas. He has been engaged in services and supports to persons with developmental disabilities since 1964. His weight management research with this population began in 2005.

A diet and incentive program was recently designed by a multi-disciplinary team including dietitians, exercise physiologists, and behavior analysts. The diet was presented in a manner that was picture-based rather than numbers-based. Each participant was seen monthly in his or her home. The diet has been tested and has been successful with adults with intellectual or developmental disabilities. The project results will be described along with insights on problems related to obesity in individuals with disabilities. Discussion will include the role of caregivers, residence type, and level of functioning.

**Break: 2:15 – 2:30**

## Afternoon Workshops 2:30 - 3:30

### **6.** *Training Methods, Materials, Incentives, and Staff Support Mechanisms in Weight Loss Interventions for Persons with Developmental Disabilities*

**Speaker: Richard R. Saunders, Ph.D.**, Senior Scientist Emeritus in the Schiefelbusch Institute for Life Span Studies at the University of Kansas.

This workshop will delve into many of the underlying factors related to success or failure on the diet approaches. Visual materials used in the diets will be shared as well as details of the incentive systems employed. A particular focus of this workshop will be the "scenario system" for guiding caregivers in supporting weight-loss efforts and, more importantly, sustaining weight loss achieved during the dieting phase.

### **7.** *Providing Health Care to Persons with Developmental Disabilities Who Have Complex Medical Problems*

**Speakers: Karen Bailey, ANC**, Nurse Practitioner; **Ted Feigelman, M.D.**, Director, Developmental Disabilities Center, Morristown Medical Center and Overlook Medical Center, Union Campus, Atlantic Health System.

This session will focus on (1) the annual physical, (2) the types of medical conditions that bring individuals with developmental disabilities to medical attention, and (3) how to treat these individuals in a manner most beneficial to persons with special needs.

### **8.** *Navigating the Transition from the NJ Division of Developmental Disabilities to the Children's System of Care*

**Speakers: Kathleen A. Enerlich, MA**, Executive Director, PerformCare New Jersey; **Theodore Kastner, M.D.**, President, Developmental Disabilities Health Alliance, Inc.; **Elizabeth Manley**, Division Director, Children's System of Care, NJ Department of Children and Families; **Jacqueline Moskowitz**, Executive Director, Family Support Center.

Children and youth with developmental disabilities, under the age of 21, are now served by the Children's System of Care within the NJ Department of Children and Families (DCF). The panelists will address: (1) the organization and delivery of services in the Children's System of Care (CSOC); (2) the role of PerformCare in administering the CSOC; (3) the transition of developmental disabilities providers into the CSOC; and (4) the experience of families and children. Questions from the audience are invited, with the request that they address systemic concerns rather than the service needs of any specific individual.

### **9.** *Advocacy for Persons with Developmental Disabilities Who Are Hospitalized*

**Speakers: Theresa Edelstein**, Vice President of Post Acute Care Policy, New Jersey Hospital Association; **Kristen Creed, MS, LPC**, Director of Health Services, The Arc of Monmouth's Ambulatory Care Center; **Maria Marquette, RN**, The Arc of Monmouth's Ambulatory Care Center.

These speakers will discuss ways to help persons with developmental disabilities have the best outcome if they are hospitalized. The discussion will focus on these areas: (1) Recent regulations from the Centers for Medicare and Medicaid Services (CMS) that may impact care in the hospital and access to an inpatient rehabilitation or skilled nursing facility after leaving the hospital, and (2) When an individual with a developmental disability is hospitalized for a physical or mental health issue, the quality of care received and the coordination of that individual's discharge often depends on knowledgeable advocacy from the individual's support team. Examples from various hospital scenarios will be discussed and recommendations for specific advocacy will be provided.

### **10.** *End-of-Life Decisions for Adults with I/DD: Considerations for the Surrogate Decision Maker*

**Speakers: Jessica Anastasi**, Director, NJ Bureau of Guardianship Services; **Joe Young**, Executive Director, Disability Rights New Jersey.

The provision of appropriate end-of-life treatment for terminally ill individuals with developmental disabilities can raise some special ethical concerns, particularly for individuals with developmental disabilities who are receiving services from the State of New Jersey. Persons with developmental disabilities, as any other citizen, have the right to receive quality palliative care and the right to refuse medical treatment. This workshop will provide information on the ethical and legal principles that provide guidance to Surrogate decision makers -- including guardians from NJ's Bureau of Guardianship Services -- when making end-of-life decisions.

**FOR FURTHER INFORMATION, INCLUDING EXHIBITING OPPORTUNITIES, PLEASE CONTACT:**

**Mainstreaming Medical Care Program,**

Helen Rivera, Administrative Assistant

Phone: 732-246-2525, ext. 35 • Fax: 732-214-1834

e-mail: [hrivera@arcnj.org](mailto:hrivera@arcnj.org)

*Register Here or Online at*  
[www.mainstreamingmedicalcare.org](http://www.mainstreamingmedicalcare.org)  
Registration deadline: **May 17, 2013**  
Early registration is advised!

Please print

Name \_\_\_\_\_

Phone \_\_\_\_\_

Affiliation/Title \_\_\_\_\_

APN-C License # and state code,  
if applying for AANP CE credits \_\_\_\_\_

Agency and Address \_\_\_\_\_

\_\_\_\_\_

E-Mail Address \_\_\_\_\_

## Registration Fee

Please make checks payable to: The Arc of NJ

- ☐ \$65 includes Continental Breakfast and materials.  
(If having lunch on your own, restaurants and a food court are available at Forrestal Village.)
- ☐ \$95 includes Lunch, Continental Breakfast and materials.
- ☐ **Provider Agency Discount:** For every 4 registrations from the same non-profit agency, 5th employee attends free (discount applies only to registrants selecting the same registration option: either "lunch" or "no lunch"; please send all registrations together).
- ☐ Scholarship (limited availability—first come, first served—medical students, residents, or others in need; call Ms. Rivera at 732-246-2525 ext. 35 **before** registering).

If having Conference Luncheon, please select one:

- ☐ Chicken    ☐ Vegetarian  
☐ Special dietary request. Please specify:

\_\_\_\_\_  
☐ Visa    ☐ MasterCard    ☐ Discover    ☐ American Express

☐ **Credit Card #** \_\_\_\_\_

Signature \_\_\_\_\_

Exp. Date \_\_\_\_\_

☐ Sign language interpreter. Request by May 1st.

**Refund Policy:** Refunds will not be given for cancellations made after May 21, 2013 or for no-shows.

## Workshop Choices

Please circle the number of your 1<sup>st</sup> choice a.m. and p.m., and 2<sup>nd</sup> choice a.m. and p.m. Early registration is advised to assure your first choice of workshops.

### 1<sup>st</sup> Choice

a.m. 1 2 3 4 5  
p.m. 6 7 8 9 10

### 2<sup>nd</sup> Choice

a.m. 1 2 3 4 5  
p.m. 6 7 8 9 10

Please mail or fax this form to:

Mainstreaming Medical Care  
24th Annual Conference - The Arc of New Jersey  
985 Livingston Avenue  
North Brunswick, NJ 08902-1843  
Fax: 732-214-1834

## The Arc and Mainstreaming Medical Care

Established 64 years ago, The Arc of New Jersey is a private not-for-profit organization affiliated with The Arc of the United States and committed to enhancing the quality of life of children and adults with intellectual and developmental disabilities and their families through advocacy, empowerment, education and prevention. The Arc of New Jersey is comprised of a state office and local county chapters serving all 21 NJ counties.

Mainstreaming Medical Care is a special program of The Arc of New Jersey that advocates for accessible, quality health care for individuals with intellectual and developmental disabilities in New Jersey. Funding for the program is provided by the New Jersey Division of Developmental Disabilities, and is also made possible through grants and other private donations.

### Conference Objectives

The primary objectives of this conference are:

- 1) To increase knowledge about new programs and policies for children and adults with developmental disabilities who receive services from the NJ Dept. of Children and Families or the NJ Department of Human Services.
- 2) To increase knowledge about health and mental health services for persons who have been diagnosed as having both an intellectual disability and a mental health disorder.
- 3) To increase knowledge of state-of-the-art services and treatment modalities to improve the medical and dental health, fitness and well-being of persons with intellectual and other developmental disabilities.

### Audience

This conference is for everyone who is concerned about providing quality health care to individuals with intellectual and other developmental disabilities including: health and mental health professionals; administrative and direct care staff at agencies providing services to persons with intellectual and other developmental disabilities; family members; social workers; HMO representatives; and employees of the New Jersey Departments of Human Services, Children and Families, and Health and Senior Services.

### Accreditation

Everyone who attends will receive a Certificate of Attendance. Certificates of Attendance will only be distributed at the end of the afternoon workshops. Application for CME credit has been filed with the **American Academy of Family Physicians (AAFP)**. Determination of credit is pending.

This program is pending CE approval with the **American Academy of Nurse Practitioners (AANP)** and the **Commission for Case Manager Certification (CCMC)**.

## Directions to the Westin Princeton Forrestal Village

201 Village Boulevard • Princeton, NJ 08540 • (609) 452-7900

The Westin Princeton is located in the Forrestal Village, on Southbound Route 1 in Princeton, NJ. Please note: Whether you are traveling north or south on Route 1, use the exit marked "Forrestal Village." For directions, please contact Helen Rivera by phone: 732-246-2525, ext. 35 or email: [hrivera@arcnj.org](mailto:hrivera@arcnj.org)

The Westin is offering a discounted room rate of \$179 for the evening of May 30th. To reserve a hotel room, call 609-452-7900 and indicate that you will be attending The Arc of New Jersey's conference. **This discount rate is available until Wednesday, May 1st.**