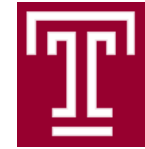


# On Your Mark:



## A CBPR Partnership on Obesity in Children with Disabilities

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Jeffrey Cooper, MBA, MS, Community PI  
Mary Segal, PhD, Academic PI

**Lessons Learned:**  
**Engaging Diverse Communities in Obesity Research**  
National Institutes of Health  
April 29, 2013

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## Project significance

The overall purpose of this project is to establish a **regional academic-community partner network** to identify community-based research priorities and develop a long-term collaborative agenda to 1) reduce obesity risk and 2) promote long-term health in **school-age children with developmental disabilities (DD)** such as autism and intellectual disabilities.



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□ History of our partnership

2007	2008	2010	2011	2012
Evaluation Of Healthy Lifestyles in Day Programs	RO3 for CBPR	U13 Networking Grant	R21 for Group Homes	RO3 on Kids' PA (submitted)



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□ **Project specific aims**

- 1) Build a **strong working relationship** and a set of research goals focused on community priorities in addressing and reducing health-disparities through a series of inter-related meetings, workshops and community forums.
- 2) **Provide health education** about the problems related to childhood obesity in a manner that is sensitive to the community's perceptions of their experiences, e.g. stigma, regarding this area of health disparities.
- 3) Outreach to the community to **identify stakeholders' areas of interest** in addressing disparities in obesity and provide expert consultation to the community about research-related topics that they identify as important.
- 4) Implement a **Memorandum of Understanding** between Temple University and one or more community organizations in the network for the purpose of developing a CBPR agenda on health disparities in obesity for this population.



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- Children with functional limitations in physical activity are approximately 2.3 times more likely to be overweight than children without such limitations (Minihan, Fitch and Must, 2007). Heightened risk factors include medication use, unhealthy diets, mobility limitations, family stressors associated with the financial strain of having a child with developmental disabilities, and lack in many schools of specialized resources to tailor nutritional or physical activity-related interventions.

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□ Project partnership structure



**“Umbrella” organization re children: Capital Area Intermediate Unit**

**Two advocacy organizations:**

**UCP of Central Pennsylvania**

**ARC of Cumberland County**

**Two county agencies:**

**Dauphin County I/DD**

**Cumberland-Perry Counties I/DD**

**One academic affiliate:**

**Temple University Center for Obesity Research and Education  
(CORE)**

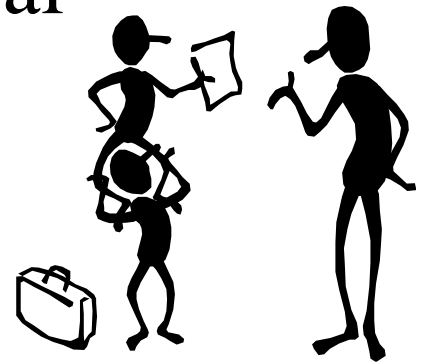
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□ Identifying key stakeholders

The project partners were tasked with identifying members for the Advisory Board, approximately 3-4 from each partner.

Advisory Board included the Medical Director of the Commonwealth's Office of Developmental Programs



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□ **County and Commonwealth representatives**

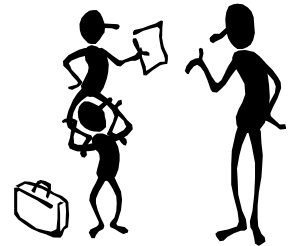
**Susan Carbaugh** - Cumberland County IDD, Director

**Joy Hafer** - Dauphin County IDD

**Shirley Keith-Knox** - Dauphin County IDD, Director

**Jill Morrow-Gorton** - Medical Director, PA Office of  
Developmental Programs

**James Richards** - Cumberland County IDD





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□ **Advocacy agency staff**

**Cindy Adams** - Arc of Cumberland County

**Winnie Black** - Arc of Dauphin/Lebanon Counties

**Barry Claypool** - UCP Central PA

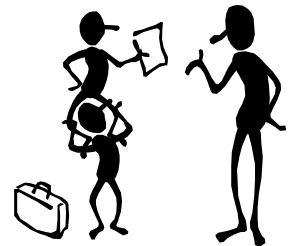
**Deb Eslinger** - UCP Central PA

**Vincent Gurreri** - Arc of Cumberland County, Director

**Barb Jumper** - Arc of Dauphin/Lebanon Counties,  
Director

**Kathy Seiderer** - UCP Central PA

**Lucy Zander** - Arc of Cumberland County



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□ **Community volunteers and family members**

**Brian Keefer**

**Bill Schultz**

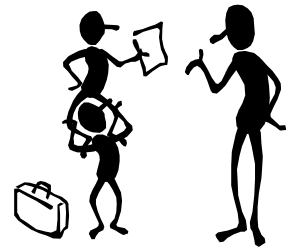
**Fran Shade**

\* **Maggie Barbush**

\* **Abby Zonarich**

\* **Elizabeth Zonarich**

\* **Students age 11 - 18**



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□ **Educators and therapists**

**Donald Dupes** - High school teacher

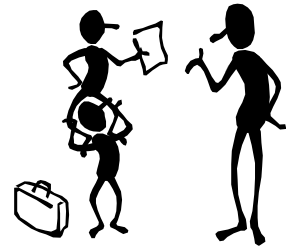
**Elaine Karl** - High school teacher

**Suzanne Knouse** - Elementary school teacher

**Cheryl Park** - Capital Area Intermediate Unit

**Amy Swartz** - Early intervention director

**Kathy Zonarich** - Physical therapist





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□ **Consultants**

**Myles Faith, PhD** - Associate Professor of Nutrition,  
University of North Carolina

**Aviva Must, PhD** - Professor and Dean, Tufts  
University Public Health and Professional Degree  
Programs

**Ronald Williams, MD** – Internist and Pediatrician,  
Penn State Hershey Medical Center

# R13HD063168 on Obesity in Children with Disabilities

## United Cerebral Palsy of Central PA and Temple Univ. School of Medicine

### □ Ready Set Go for Health website

Resources for Exercise  
**Ready Set Go!**  
Activities and Diet for You

Visit the UCP of Central Pennsylvania Website

Text Size: [A](#) [A](#) [A](#) | [Contact Us](#) Search the Site

[DONATE NOW](#)

What is Obesity

Nutrition

Benefits of Exercise

Activity Calendars

Sample Exercise Videos

Resources

Contact Us

Ready Set Go for Health... taking steps towards a healthier future for individuals with disabilities and their families.

It is widely recognized that the earlier in life that children are introduced to exercise and nutritional guidelines, the more likely they will carry those habits into adulthood.

The Ready Set Go for Health website is the primary focus of the READY (Resources for Exercise Activities & Diet for You) Project established through a joint Temple University/UCP Central PA initiative which aims to reduce the risk of obesity in children with disabilities. The initiative is funded through a grant by the National Institutes of Health (NIH# U13HD063168).

The project was set up by a volunteer group, with the help of several community members who learned about the READY project at a grant-sponsored Community Forum. The group met once a quarter to help develop a website to provide children with disabilities and their parents with resources they can use to lead healthier lives.

Activity Calendar

**GET IN TOUCH**

Monica Lazur  
Project Manager  
Ready Set Go For Health  
UCP Central PA  
Tel: 717.975.0611 x 220  
Fax: 717.975.0839  
[Contact Monica](#)



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□ Assessing the community's priorities



□ At Community Forums

□ Most successfully, using a questionnaire distributed by the CAIU and other project partners to parents. The survey was available on the internet (SurveyMonkey) as well as in hard copy.



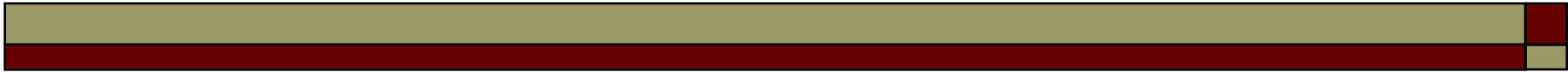
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- ❑ **Results from family surveys:**
- ❑ 150 valid responses from the 3-county area
- ❑ 40% of the children were overweight
- ❑ 80% of the children had intellectual disabilities
- ❑ 30% of the children had physical disabilities
- ❑ 48% of the children were girls







- **Importance of & satisfaction w/ health promotion**

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- Parents' ratings of **physical activity opportunities**
- Affordable individual or group exercise for child:  
**Definitely important: 67%\***      **Definitely satisfied: 19%**
- Child learn about kind and amount of physical activity:  
Definitely **important: 59%**      Definitely **satisfied: 20%**
- Parent learn about kind and amount of physical activity:  
Definitely **important: 59%**      Definitely **satisfied: 31%**
- Affordable team sports for child:  
Definitely **important: 54%**      Definitely **satisfied: 24%**

\*Significantly more important if child was underweight (16% of sample) or overweight/ obese (36% of sample). Interest in improving phys. act. was less if child was underweight (58% said “yes”) than normal/overweight/obese (82% said “yes”).

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- Major challenge: Involving families in forums

Although - we tried various formats, days and times, seasons, venues, child care and refreshments were provided and advertised, expert speakers were presenters, health fair format was featured, events were advertised well in advance and distributed through many channels to the community.





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□ Partnership evaluation

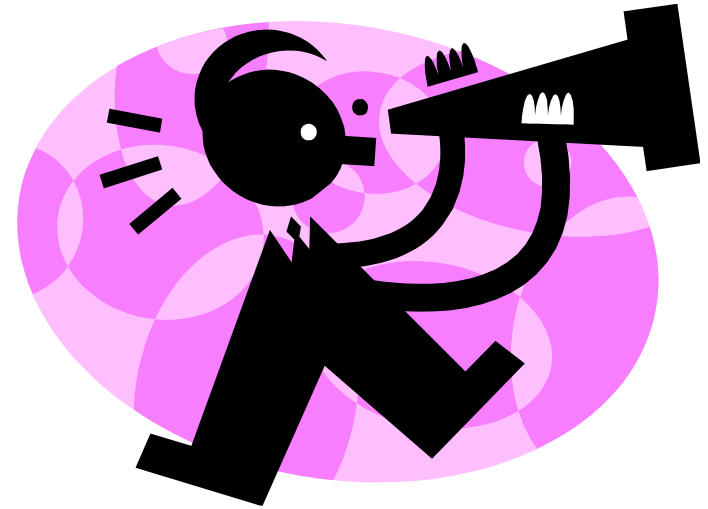
- Written quantitative evaluations and reflection time after each Board meeting
- Community Forum written evaluations
- Annual reports to County agencies
- RO3 proposal progress

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□ Future directions

- MOU draft is circulating
- Proposal is under revision
- New plans for involving families are under consideration



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□ Questions, comments?

