

The largest service provider of its kind in the state of New Mexico, ARCA is a nationally accredited, nonprofit organization dedicated to providing quality services to people with developmental disabilities and mental retardation. ARCA serves over 450 individuals a year and offers an array of premier services including:

#### Residential Services

ARCA offers assisted and supported community living options in beautiful, safe homes. Additionally, we provide door-to-door transportation, social services support, nutritional guidance, therapy, and community-sponsored social outings.

# Respite Services

Our program provides flexible family support services, allowing families to rest from their roles as primary caregivers while trained professionals assist their loved ones with daily living activities.

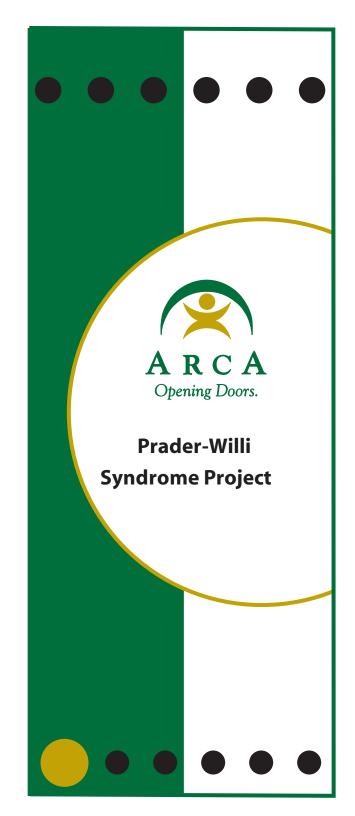
#### Vocational Services

ARCA provides tailored services, including a literacy enhancement program, to address individualized interests in work and career opportunities.

For more information about ARCA visit our website at www.ARCAOpeningDoors.org or call us at 505-332-6700.







# Prader-Willi

# **Syndrome Project**

The only program of its kind in the nation, ARCA'S Prader-Wiili Syndrome (PWS) Project is a statewide program offering consultation and specialized case management for individuals with this life threatening genetic disability.

We are dedicated to promoting an increased awareness and understanding of PWS. We provide written information, training, conferences, and seminars to individuals and groups interested in learning more about PWS.

## **Our Mission**

The mission of the Prader-Wiili Syndrome Project for the state of New Mexico is to identify individuals with PWS and to assist these individuals and their families in finding services that will promote their health and allow them to choose and achieve their life goals and fully experience community life.

## For More Information

For more information or to refer individuals for services please contact us:

<u>Statewide</u> 1-844 302-6868

Albuquerque
(505) 243-3817 office
(505) 550-1550 cell
Penny Chavez
PWS Project Case Coordinator
pchavez@arcaspirit.org

Michelle Harmon - Director 505-332-6843

# **Prader-Willi Syndrome**

# **Project Support Services**

# **Identification and Diagnosis**

If PWS is suspected, we will direct families to a geneticist who can complete diagnostic testing.

## **Case Management**

Our program provides assistance in locating, developing, and coordinating individualized resources and services for the management of PWS in a person's home community.

#### **Nutrition Consultation**

A nutritionist develops an individualized Medical Nutrition Therapy program for each person served. We also provide nutrition consultation to other service providers.

#### **Residential Services**

We work with individuals and their families to develop living arrangements designed to meet individualized needs.

## **Behavioral Supports**

Our program provides behavioral training, consultation, and support to individuals, their families, and other service providers.

## **Family Supports**

We provide families with essential information regarding PWS and available support services, including benefits and guardianships. Additionally, we assist families in the development of individualized service plans.

# **Emergency Respite**

Our program provides families with funds for respite services on an emergency basis. Prior approval is required for this service.

## **Training and Education**

We offer training and education to providers who serve individuals with PWS.

# Characteristics of Prader-Willi Syndrome

Affecting 1:12,000 to 15,000 live births, Prader-Willi Syndrome (PWS) is a genetic disorder with no known cure. If left untreated PWS can lead to morbid obesity and death.

#### **Characteristics of PWS**

- The Hypothalamic and other regions of the brain are not functioning resulting in:
  - o **Hypotonia** Low muscle tone affecting all muscles in the body.
  - o **Hyperphagia** Insatiable appetite leading to uncontrolled eating and searching for food.
  - o **Hypogonadism** Small genitalia and lack of sexual maturity.
  - o **Hypomentia** Learning disabilities and/or mental retardation.
- Emotions that are unmodulated and can lead to emotional outbursts, temper tantrums, and mood swings.
- Behavior that is inflexible and can lead to stubbornness, hoarding, self-trauma, and aggression.
- An experience of pain and illness that is different from people who do not have PWS.

## **Other Characteristics**

- Short stature
- Almond-shaped eyes
- Thin, tented upper lip
- Pear-shaped body type
- Low pigmentation
- Different facial proportions
- Small hands/feet with a straight ulnar border on the side of the hand