
RESOURCE AVAILABLE

Division of Developmental Disabilities (DDD)

Call your local office or call
1-800-321-2808
to get the number of your area.

Angelman Syndrome Foundation

414 Plaza Dr, Ste 209
Westmont, IL 60559
1-800-432-6435

Washington Reps: (253) 474-4865 or
(360) 892-9552

Website: www.wasf.com

The information in this brochure is an adapted form material provided by the Angelman Syndrome Foundation.

It is the policy of Washington PAVE that no person will be subjected to discrimination in this organization because of race, color, national origin, marital status, sex, age, religion, sexual orientation, HIV/AIDS status, disabled or Vietnam Era veteran status, or the presence of any physical, mental, or sensory disability.

Washington PAVE Parent-to-Parent Training Offices

Kitsap County Office

327 Pacific
Bremerton, WA 98337
Ph/Fax*51: (360) 479-6657

Spokane Office

PMB #482 816 Francis Ave.
Spokane, WA 99205-6512
(509) 326-1722 (v/tty)
Fax (509) 326-1835
E-mail: pave@ieway.com

Sunnyside Office

105 South 6th #B
Sunnyside, WA 98944
(509) 837-8909 (v/tty)
Fax: (509) 839-5803
1-877-821-4113

E-mail: sherrymash11@hotmail.com

Castle Rock Office

PO Box 775
Castle Rock, WA 98611
Ph/V/Fax*64: (360) 274-0316
E-mail: wapave@tdn.com

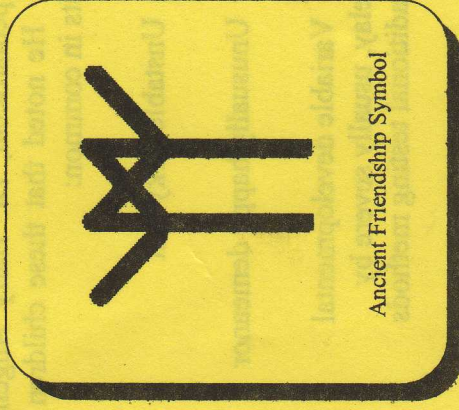
Yakima County Office

PO Box 8014 Yakima, WA 98908
(509) 972-4659
E-mail: sheehanabd@bentonrea.com

Children and youth with disabilities have the right to a free appropriate public education.

IDEA '97

PAVE



Advocacy Bulletin #13
Tips for Parents of Children with

Angelman Syndrome

Washington PAVE
Statewide Parent Training and
Information Center
6316 So. 12th St.
Tacoma, WA 98465
(253) 565-2266 (v/tty)
1-800-5-PARENT (v/tty)
E-mail: wapave9@washingtonpave.com
Web site: www.washingtonpave.org

WHAT IS ANGELMAN SYNDROME?

Angelman Syndrome, (AS), is a genetic disorder first described by an English pediatrician, Dr. Harry Angelman, in 1965. He noted that these children had some traits in common:

- ◆ Unstable jerky gait
- ◆ Unusually happy demeanor
- ◆ Variable developmental delay, usually severe by traditional testing methods

- ◆ Lack of speech/few words-receptive language skills may be much higher than expressive language skills

- ◆ Small head size

- ◆ Seizure disorder

Other features often noted are sleep disturbances, flattened back of the head, excessive drooling, chewing and other oral behaviors, hyperactivity, light skin, eye, and hair colors (when compared to other family members), wide-based gait, and feeding problems in infancy.

Many more diagnoses are being made of what was until recently thought to be an extremely rare disorder.

Currently, approximately 1000 individuals with AS have been identified in the U.S. and Canada combined! It is believed that thousands more remain undiagnosed, or misdiagnosed with cerebral palsy, autism, or other disorders.

Males and females are affected in equal numbers.

Both early diagnosis and intervention can be beneficial when AS is suspected.

Diagnosis can now be accomplished in the first year of life.

SCHOOL PROGRAMS

Children with Angelman Syndrome need special education just as other children do who have severe developmental delays. A full range of early intervention training and enrichment programs should be available. Unstable or nonambulatory children may benefit from physical therapy. Occupational therapy may help severely unstable children achieve better fine motor and oral-motor control. Language and communication therapy is essential and should focus on nonverbal methods of communication. Extremely active and hypermotoric children will need extra care in the classroom. Children usually need room to express themselves and to "grapple" with their hypermotoric activities.

The classroom setting must not be so structured, either in its physical design or in its curricular program, that the active child cannot fit in or adjust to the expectation

there. Individualization and flexibility are important.

Consistent and persistent behavioral training in school and family settings can enable the child to be toilet trained and to perform most self help skills such as eating, dressing and performing general activities. Children with Angelman Syndrome often cannot attend to tasks easily or may have persistent stubborn behaviors so the school should have the resources to impose a consistent behavioral modification program.

REMEMBER:

- Parents are experts on their child.
- Parents are members of the IEP team.
- The program must be individualized to meet the child's needs.
- Open communication with the teachers is invaluable.
- Parents can call an IEP meeting at any time equal numbers.

"Your child may be eligible for SSI payments. Contact your local Social Security Office for more information".