

FOCUS ON AUTISM

GOVERNOR'S PROJECT: NEW JERSEY DISTRICT OF KIWANIS INTERNATIONAL

The Challenge

We have all experienced it. You are in a crowded store. A child throws a tantrum. The embarrassed parent tries to pacify the child. What is your first thought? Is this an unruly kid who needs to be disciplined in the good old fashioned way? Or do you wonder, "Could this be one of the millions of children who suffers from autism?"

Autism and autistic spectrum disorders are developmental disorders whose symptoms usually first appear during a child's first three years of life. It is caused by abnormal development of the brain and is a life-long disability.

Children with autism typically have problems with verbal and non-verbal communication, impaired social interactions, and unusual or limited interests and activities.

Since autism was first diagnosed six decades ago, the incidence of this disorder has increased. During the past decade it has grown seven-fold. It has been estimated that by the year 2010 nearly four million Americans will have the disorder. It has been estimated that it will cost nearly four million dollars to treat an autistic person

throughout his or her lifetime.

Researchers are working to find what causes autism and how it can be cured.

Early diagnosis and early intervention are vital to help many autistic children grow up to lead normal lives. Screening instruments have been developed to provide an accurate diagnosis of autism and therapies have been implemented to alleviate inappropriate behavior and improve life-necessary skills.

Parents whose children are suspected of being autistic need to know that help is available for them and their child.

The Opportunity

Kiwanis clubs are in a position to assist autistic children, their families, and the professionals who care for them.

By utilizing their resources clubs can educate the public and parents about autism. Clubs can provide respite care for the caregivers who minister to the

needs of an autistic child. And clubs can assist with fund-raising to speed up research to find a cure.

Kiwanis clubs can urge local lawmakers to pass a resolution that heightens the community's awareness of autism. They can distribute brochures to parents of young children that teach parents to look for warning signs of autism.

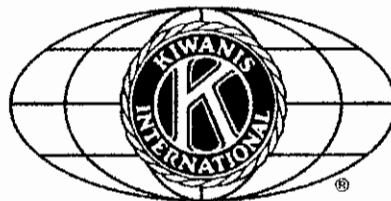
Kiwanis clubs can initiate support groups for families with autistic children. And they can fund a lending library that enables parents to learn more about their child's condition.

Autism explained

Autism is a complex developmental disorder that typically appears during a child's first three years of life.

It is a biological condition that results in a life long disability. While experts disagree whether autism is curable, parents need to know that if autism is treated early many children can go on to lead normal lives.

Autism symptoms center around three broad areas: problems with verbal and non-verbal communication; impaired social interaction; and unusual or limited interests and activities.



Autism is the second most common developmental disability, trailing only mental retardation.

Researchers estimate that six to seven children per thousand are affected by autism. The US Department of Education reports it is growing at the rate of ten to seventeen percent each year. The Autistic Society of American predicts that at those rates, autism could affect four million Americans by the next decade.

The overall incidence of autism in the US is similar to that around the world.

Autism knows no bias. It strikes all races, ethnic and social groups, and both sexes, though boys are four times more likely to develop it than girls.

In families where one child has developed autism, there is a five percent chance of siblings also developing the condition. That is ten times greater than the rate in the general public.

It appears from research that at least some children are born with a susceptibility to autism, but scientists have not been able to identify a unique factor that triggers it to develop.

Several factors are being investigated, including:

- genetics, though to date no single gene abnormality or mutation has been found;
- early fetal development, especially in the first twenty to twenty four days after conception, and;
- environmental exposures such as viral infections, metabolic imbalances, and exposure to

environmental chemicals.

The federal government has ruled out autism's relationship to vaccines, yet some independent scientists still believe a link exists between autism and thimerosal, a mercury containing preservative used in some vaccines, or with the MMR (mumps, measles, rubella) vaccine.

Autism has also been linked to fetal alcohol syndrome, to the rubella virus infection during pregnancy, and to fetus harming medications taken during pregnancy.

While no single cause for autism has been found there are certain myths about the condition that have been ruled out.

It is not a communicable disease. One does not contract it from another person, nor is it triggered by an emotional trauma. It is not caused by bad parenting. It is not a mental disease. It is not simply unruly children choosing not to behave.

Autism is a spectrum disorder. Some of it's symptoms can be severe in one child and perhaps not present in another.

Some symptoms include: not responding to his or her name; inability of the child to explain what he or she wants; delayed language or speech skills; inability to follow directions; deaf-like; failure to point or wave; intense or violent tantrums; odd movement patterns; hyperactivity; uncooperative, or oppositional; does not know how to play with toys; does not smile when smiled at; has poor eye contact; gets "stuck" on things and can't

move on to other activities; prefers to play alone; gets things for him or herself only; very independent for one's age; does things early compared to other children; seems to tune people out; dwells in his or her "own world"; not interested in other children; walks on his or her toes; shows unusual attachments to toys, objects, or schedules; spending a lot of time lining things up or putting them in a certain order.

At one time or other all children have probably displayed one or more of those symptoms. But if those symptoms tend to repeat themselves or are grouped together in a consistent pattern, one should let the child's physician know. In addition, the child's physician should do a "developmental screening" during the child's regularly scheduled well-baby and well-child visits.

Pediatricians have identified various milestones that a child should achieve during his or her development. If those milestones are missed it should raise a *red flag* for parents or caregivers and be brought immediately to the attention of the child's physician.

Those milestones include:

- Does not babble or coo by twelve months of age
- Does not gesture (point, wave, grasp, etc.) by twelve months of age
- Does not say single words by sixteen months of age
- Does not say two-word phrases on his or her own (rather than just repeating what someone says to him or her) by twenty-four months of age
- Has any loss of any

language or social skill at any age.

If a child is suspected to be autistic, he or she will need to be referred to someone who specializes in diagnosing autism spectrum disorders. By law (Individuals with Disabilities Act-IDEA, 1997) the child's primary care provider is required to refer the family to an early intervention service.

There are no medical tests for diagnosing autism, though a physician may order certain tests, such as a hearing exam or test for lead poisoning.

An accurate diagnosis is made by observing a child's communication, behavior, and developmental abilities. Several screening tests have been developed to identify the condition in children as young as eighteen months old.

It has been shown that the earlier a child is diagnosed and treatment is started, the sooner a child can benefit from intervention treatments and the greater the chance of that child leading a normal life.

The Autism Society of America offers parents the following guidelines while working with professionals:

- be informed and learn as much as you can about your child's disability.
- be prepared for meetings with the professionals, writing down your questions and concerns, then noting their response.
- be organized, keeping a notebook detailing your child's diagnosis and treatments.
- communicate your concerns.

Just as autism manifests itself differently and no two children have exactly the same condition, and treatment for each will be different. Once an accurate diagnosis of autism is made it is important that parents and professionals work together for the child's benefit.

The goal of treatment is to advance a child's social and communication skills and to minimize those behaviors that interfere with the child's functioning and learning.

Professionals have three broad therapies from which to choose. Often treatment is a combination of elements from those therapies.

Early Intervention Programs (EIP) have been shown to help many children acquire skills for their self-care, and develop social and job skills. Specialized therapies, such as speech, occupational, and physical therapies, help children manage their autism.

Behavioral therapy has been used to improve communication, learning, and develop appropriate social behaviors.

Medications are also used to treat symptoms of autism as well as behaviors that are causing difficulties. They may also bring a child up to a functional level at which they can benefit from other treatments.

It is almost an embarrassing understatement to say caring for an autistic child is not an easy task. Family members need training to learn to cope with an autistic child as well as to assist in the child's development. Such training has

been shown to reduce household stress. It is also important that family members learn they have a need to occasionally break away from the situation. "Burned out" caregivers become resentful and the quality of their life and the care they offer suffers.

Families can also find relief by networking with other families who have an autistic child. Sharing their concerns lets them know they are not alone. It also enables them to learn time proven "little tricks" to assist them in the care they provide.

Finally, it is important that the community becomes aware of the world of autism. Kiwanis is in a unique position to inform the public of the needs of autistic children and their families.

Partner Organizations

The New Jersey Center for Outreach and Services for the Autism Community (COSAC) is a non-profit agency providing information and advocacy, services, family and professional education, and consultation to New Jersey's autism community. www.njcosac.org It offers information in English, Spanish, and French. Their phone number in NJ is 1-800-4-AUTISM (1-800-428-8476).

National Alliance for Autism Research (NAAR), funds research to determine the causes, prevention, treatment and ultimately a cure for autism: www.naar.org Their phone number is 888-777-NAAR (6227).

Additional resources

US government resources:

MEDLINE Plus, a service of the National Library of Medicine (NLM) offering access to all the NIH resources about autism: www.nlm.nih.gov/medlineplus then perform a search for autism.

National Center on Birth Defects and Developmental Disabilities, autism information center offering information on specific state autism programs that are funded by the Center for Disease Control (CDC): www.cdc.gov/ncbddd/dd/ddautism.htm

National Institute of Child Health and Human Development: www.nichd.nih.gov/autism or 1-800-370-2943.

National Institute of Environmental Health Sciences: www.niehs.nih.gov search for autism.

National Institute of Neurological Disorders and Stroke, the nation's leading supporter of biomedical research on disorders of the brain and nervous system: www.ninds.nih.gov/health_and_medical/pubs/autism.htm

Public and private agencies:

American Academy of Pediatrics, www.aap.org search for autism.

The Arc, a national organization for mental retardation, <http://thearc.org>

ASPEN ® is a regionally-based non-profit organization headquartered in New Jersey, with 12 local chapters, providing education, support, and advocacy to families and those individuals affected with Asperger Syndrome, PDD-NOS, High Functioning Autism, and related disorders: www.aspennj.org

Aspergers Disorder information: www.aspergers.com

Autism Society of America. In English: www.autism-society.org In Spanish: www.autism-society.org/site/DocServer/autismo.pdf?docID=362 The society offers free classes on autism awareness on-line.

Cure Autism Now (CAN) Foundation, www.canfoundation.org believes that with enough determination, money and manpower, science can be hurried so that answers are found sooner rather than later.

First Signs is dedicated to the early identification of children with developmental delays and disorders: www.firstsigns.org

International Rett Syndrome Association, www.rettsyndrome.org

Kidshealth, sponsored by the Nemours Foundation: www.kidshealth.org Information is also available in Spanish: www.kidshealth.org/parent/en-espanol/index.html

March of Dimes Birth Defects Foundation, <http://www.marchofdimes.com>

Passive Developmental Disorders information: <http://info.med.yale.edu> Perform a search for passive developmental disorders.

Rett Syndrome Research Foundation, www.rsrf.org

Support groups:

The Autism Network offers on-line help to questions and concern parents have regarding their autistic children. www.autism-network.com

The Drive for Rebecca, www.driveforrebecca.org offers portions of "The Special Needs Caregiver Survival Guide," offering practical advice to parents with children who have special needs.

National Respite Locator Service helps parents, caregivers and professionals find respite services in their state: www.respitelocator.org/index.htm

Respite care is also available from Autism Family Services of New Jersey: www.efnj.com. Their phone number is 609-392-4900.

For a list of autism organizations around the world see the Action for Autism (AFA) website. AFA is the largest and only national, non-profit autism organization of India. <http://www.autism-india.org/worldorgs.htm>

Project Ideas

Create a reference library

Parents need information about autism spectrum disorders. They need to know what it is and how it can be treated, as well as contact information for public and private programs designed to help them and their children.

Information is available from local and national health agencies. Contact information for them and national organizations that exist to support families and research programs can be found in this booklet.

Books may be ordered through those groups. Some videos and audio tapes are also available.

Ask your local autism specialist for reference materials recommendations. Encourage the specialist to refer parents to that library.

Ask your local hospital for a corner where you can place the library. Donate materials to your community library. Keep it stocked with up-to-date information.

Host a support group for parents of autistic children

A support group enables parents to meet with other parents of autistic children.

By meeting with other parents tips are shared. So are the many small victories and major concerns they face daily.

Find a facilitator to lead the group's sessions. Your local

hospital may be able to suggest someone.

Find a location that is comfortable and convenient, and provide light refreshments.

Host a family respite night

Gather the families for a night out together. Organize a theme party. Or maybe a movie night? Perhaps a sporting activity, like bowling, basketball or volleyball.

Be creative! Perhaps a group of Kiwanians can "babysit" while the parents go out for a private dinner. Just be sure you have training to care for autistic children and contact information in case you need to get hold of the parents in an emergency.

Work with your local school board

Children with autism are guaranteed access to a full and thorough education. Often a school district is ill equipped to meet some of the children's special needs.

Ask! There may be items the club can provide. It may be something major, like a computer or special gym equipment. Or minor, like supplies

Fundraisers! Fundraisers! Fundraisers!

There is no end to the financial strain autism places on families. Insurance and governmental programs pay for just so much. But there are other family obligations that need to be met

and siblings that must not be ignored.

Researchers are busy at work not only developing new treatments and strategies to overcome autism, but also trying to discover what it is that triggers the disorder. Find a local or national group you would like to support.

Hospitals judiciously commit scarce resources as they treat autistic children. Perhaps your club could fund a fellowship or make a donation specifically towards its autism program.

Educate yourself and your community

Invite a speaker from the local or national groups to tell your club about autism and what is being done to treat it.

Host a community forum and discuss the disorder with your neighbors.

Feel free to copy the flyer at the back of this booklet and place them in pediatrician's offices and hospital pediatric waiting areas.

Present parents of autistic children with a record book to track their child's progress

Kiwanis has developed a reproducible book that enables parents to keep track of their child's treatment and progress, visits with professionals. Copy the pages and present them in a loose leaf binder. Encourage parents to use it.

Autism Awareness Month
Sample Proclamation

Whereas, autism is a pervasive developmental disorder affecting the social, learning, and behavioral skills of those affected by it, and

Whereas, autism was once thought to be a relatively rare disorder, affecting only one in ten thousand people, and

Whereas, as more and more health professionals become proficient in diagnosing autism, more children are being diagnosed on the autistic spectrum, resulting in rates as high as six in one thousand children, and

Whereas, while there is no known cure for autism, yet, it is well documented that if an individual with autism receives treatment early in their lives, it is often possible for that individual to make significant improvement, and

Whereas, Kiwanis International is spearheading an awareness effort in order to educate parents, professionals, and the general public about autism and its effects,

Now, therefore be it resolved that I, (insert Mayor's name), do hereby proclaim (insert month, year) as AUTISM AWARENESS MONTH in the (insert municipality name) and urge all employees and residents to participate in our municipality's Autism Awareness Month activities in order to become better educated on the subject of autistic spectrum disorders.



(Mayor's signature)

**Young Children
PRIORITY ONE**

Dated: _____

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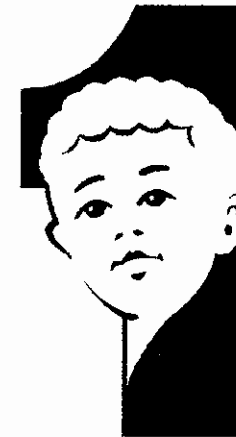
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- be organized, keeping a notebook detailing your child's diagnosis and treatments.
- communicate your concerns.

Websites of interest:

Autism Society of America, www.autism-society.org
Cure Autism Now Foundation, www.canfoundation.org
National Institute of Health, www.nih.gov
National Alliance for Autism Research, www.naar.org
MEDLINE Plus, a service of the National Library of Medicine, www.nlm.nih.gov/medlineplus

Autism Awareness



Young Children
PRIORITY ONE

a project of
Kiwanis International
Young Children Priority One

What is autism?

Autism is a complex developmental disorder whose symptoms typically appear during a child's first three years of life. Because it is a spectrum disorder some of its symptoms can be severe in one child and perhaps not present in another.

It is a biological condition that results in a life long disability. While experts disagree whether autism is curable, parents need to know that if autism is treated early many children can go on to lead a normal life.

Autism is caused by abnormal development of the brain. Its symptoms center around three broad areas:

- problems with verbal and non-verbal communications;
- impaired social interaction;
- unusual or limited interests and activities, often times repetitive.

Autism knows no bias and it strikes all races, ethnic and social groups, and both sexes, though boys are four times more likely to develop it than girls.

What causes autism?

- Several factors are being investigated, including:
- genetics, though to date no single gene abnormality or mutation has been found;
 - early fetal development, especially in the first twenty to twenty four days after conception; and
 - environmental exposures such as viral infections,

metabolic imbalances and exposure to environmental chemicals.

While no single cause for autism has been found there are certain myths about the condition that have been ruled out.

It is not a communicable disease, one does not contact it from another person, nor is it triggered by an emotional trauma. It is not caused by bad parenting. It is not a mental disease and it is not simply unruly children choosing not to behave.

Is there hope for a child with autism?

It has been shown that the earlier a child is diagnosed and treatment started, the sooner a child can benefit from intervention treatments and the greater the chance of that child leading a normal life.

The goal of treatment is to advance a child's social and communication skills and to minimize those behaviors that interfere with the child's functioning and learning.

What are the warning signs?

Pediatricians have identified various milestones a child should achieve during his or her development. If those milestones are missed it should raise a **red flag** for parents or caregivers and be brought immediately to the attention of the child's physician.