**TOPIC:** Communicating with individuals who have various physical, psycho-social, developmental, and learning disabilities that may be adversely affecting communication.



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### INTRODUCTION

• This program is designed as an educational tool for fire department "first responders" and children in special education classes who may have difficulty communicating during emergencies.

# There are four basic parts to the program:

A Video A Manual A Communication Booklet A Poster

The first part is a **video** depicting an emergency using the communication strategies and tools described in the manual.

The second part is the **manual** with basic information about individuals with various disabilities and communication difficulties a first responder may encounter on a call involving these individuals (in addition to the manual, a one-hour training session regarding the information is available upon request).

The third part is a **communication booklet** to be used on calls when necessary as well as an adjunct to various educational presentations fire personnel provide children.

Following the firefighter/paramedic training sessions, a **poster** depicting "first responders" as "friends" will be provided to all special education classrooms throughout the country. The poster will include both signs/icons and illustrations of first responders "in action".

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### **ACKNOWLEDGEMENTS**

#### COMMISSION ON DISABILITIES FOR SAN MATEO COUNTY

This project, TRAINING THE TRAINERS: *Communicating With Individuals Who Have Various Disabilities That May Be Adversely Affecting Communication* is sponsored by the CoD.

#### ADULT SERVICES ON AGING

Funding for development and production of 121 communication-booklets for emergency responders was provided by a grant from Adult Services on Aging, San Mateo County.

#### SAN MATEO COUNTY FIRE CHIEFS ASSOCIATION

Funding for production of 500 "Friends" posters distributed to all special education classes throughout San Mateo County.

#### MAYER-JOHNSON CO.

The picture communication symbols used in the communication booklet and the accompanying training video are provided by an agreement between Woodside Fire Protection District and Mayer-Johnson Company.

#### **FEMA**

Funding for this project was made possible, in part, under a grant provided by the Federal Emergency Management Agency. WFPD's Fire Marshal, Denise Enea, and Glenda Fuge, are responsible for writing and over-seeing completion of the project covered under this grant.

#### AD HOC COMMITTEE

Mike Fuge, Armando Muela, Dave Anderson, Catherine Archbold, Jeanne Crawford, Andy Frisch, and Glenda Fuge made up the "Training the Trainer" committee.

#### BARBARA PLETZ

This project could not have been completed without the support of Barbara Pletz, Director of Emergency Medical Services for San Mateo Country.

### **ERIN SARPA**

The "Friends" poster distributed to all special education classrooms county-wide was designed by "Erin Sarpa, E and I Designs.

#### MARK SARPA

All printing was generously donated by Mark Sarpa from progressive Solutions located in San Jose, California.

#### ERIC FUGE, MARTY DILLON, and LUCAS

Many thanks to Central County firefighter/paramedic Eric Fuge, Central County fire captain Marty Dillon, and Marty's son Lucas for modeling for the "Friends" poster.

#### LUCY CLEM AND ROB CONSANI

Thanks to firefighter/paramedic Lucy Clem and captain firefighter paramedic Rob Consani from the Woodside Fire Protection District for modeling for the older version of the "Friends" poster.

#### LAURA BUCKLEY

Thanks to Laura for writing, directing, and producing the outstanding training video.

#### SIMONDS ELEMENTARY SCHOOL

Thanks to Mrs. Lasher's kindergarten class for participating in the training video.

# **ACKNOWLEDGEMENTS**

## Jerry Nave

Thanks to captain Jerry Nave from the Woodside Fire Protection District for his help with the training video.

### **REBECCA NEWMAN**

Thanks to Rebecca for her participation in the training video.

### Selena Brown

Thanks to Selena Brown from the Woodside Fire Protection District for her assistance with this communication project.

# FIREFIGHTER/PARAMEDIC INSERVICE

TOPIC: COMMUNICATING WITH INDIVDUALS WHO HAVE VARIOUS DISABILITIES THAT MAY BE ADVERSELY AFFECTING COMMUNICATION

The information provided in this manual will cover the more common physical, psycho-social, developmental, and learning disabilities with regards to physical attributes, cognitive levels, and communication opportunities.

## I. PHYSICAL DISABILITIES

Physical disabilities include a wide variety of disabling conditions that may be the result of trauma, birth injury, genetic defects, etc. In addition, there are many conditions characterized by difficulty with muscle control, paralysis, spasticity, or other neurological deficiencies. Severity ranges from barely noticeable to severe spasticity and total dependence. Since cerebral palsy is one of the more common conditions requiring alternative communication strategies, CP and other neurological conditions will serve as examples for this presentation.

## • Diagnosis: Cerebral Palsy

Cause: Brain injury that occurs before birth, during birth, or within the first five years of life. Poor oxygen supply during or after birth is responsible for 1—15 percent of all cases. Cerebral Palsy is not a disease; it is a condition that may be the result of a disease. During the first year of life, severe illness, such as meningitis, sepsis, trauma, and severe dehydration, can cause brain injury resulting in cerebral palsy.

*Incidence:* One to two infants in every 1,000 births; approximately 500,000 people in the United States are diagnosed with cerebral palsy.

*Course:* Non-progressive, however may have many secondary problems that develop as the nervous system matures.

*Medications:* Many children and adults with CP (approximately 25%) have seizures and are on various seizure medications. Some are also on muscle relaxants.

*Risks:* These individuals may be at risk for aspirating during feeding or may have G tubes for feeding.

*Physical attributes:* Ranges from mild to maximum involvement of limbs, trunk, and head. May demonstrate extremely tense muscles, fluctuating muscle tone, or hypotonus. May have structural anomalies throughout the body, which results in poor ability to withstand upper respiratory infection or urinary tract infections.

Cognition: Varies from typical intellect to mental retardation. Approximately 40 percent of individuals with cerebral palsy have typical or near typical intelligence.

*Communication:* May have excellent receptive language skills even though expressive language is impaired. Ranges from non-verbal, use of augmentative communication device, icons, or verbal. Verbal skills may be adversely affected by poor oral motor muscle control.

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# • *Diagnosis:* Hearing impairments

Hearing impairments are defined as deterioration in hearing; deafness is profound hearing loss. Hearing loss may be the result of neurological damage, trauma, disease, etc.

*Cause:* May be inherited, birth difficulties, consequence of disease (meningitis, etc.). May be part of a syndrome but not necessarily.

*Incidence:* Unknown due to complexity of concomitant disabilities; many individuals with hearing impairments are reported using the primary diagnosis rather than "hearing impaired".

*Medications:* Same as general population.

Risks: Same as general population.

*Physical Attributes:* None, other than often wearing a hearing aide.

Cognition: Typical range unless part of a syndrome.

*Communication:* Many people with hearing loss read lips and sign language for receptive language. Expressive language varies from sign language only, to excellent speech. Other use signing and/or lip reading. Some individuals have companion dogs for hearing.

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• Neuromuscular Conditions: Muscular Dystrophy, Multiple Sclerosis, etc. There are many progressive and non-progressive disorders resulting in damage to the central nervous system. There are more than 80 autoimmune diseases alone; about 50 million Americans suffer from some form of autoimmune-related disease. Some disorders such as muscular dystrophy, multiple sclerosis, tumors or cysts of the brain, small strokes, ALS, lupus, Guillain-Barre syndrome, etc. may result in weak and poorly coordinated speech muscles.

*Cause:* May be result of variety of physical, genetic, or environmental insults before, during, or after birth. Many are genetic related conditions with possible environmental contributions.

*Incidence:* About 400,000 young adults in America have multiple sclerosis; 250,000 have muscular dystrophy.

Risks: May have hypotonus, poor gag reflex, poor swallowing, extreme exhaustion, etc.

*Physical Attributes:* May have companion dog, cane, braces, wheelchair, oxygen, etc.

Communication: Mildly or moderately affected individuals communicate same as general population. Severely involved individuals may use augmentative "voice output" devices. Receptive language usually remains intact for emergency communication purposes.

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#### II. DEVELOPMENTAL DISABILITIES

• *Diagnosis:* Autism (autistic spectrum disorder, ASD) is defined in the DSM-IV Training Manual as a disorder resulting in markedly impaired social interaction, difficulties in expressive and receptive language, unusual sensory perception, ritualistic behavior, and greatly restricted repertoire of activities and interests. It is usually diagnosed before age 3. Retrospective studies using home videos of first birthday parties have shown unusual social interaction by age one.

*Cause:* Current research supports a genetic link with environmental catalysts. Some May be related to viral infection, inherited enzyme deficiency, or fragile X syndrome (a chromosomal disorder).

*Incidence:* Latest research across the nation ~300-500% increase in last 10 years! Autism is the most common developmental disability (15-20 per 10,000). Boys out number girls two to four times.

*Medications:* Many individuals with ASD are on one or more drug regimen. Most often, one of the SSRI drugs such as Prozac is the drug recommended; others are Paxil, Buspirone, Risperidone; 20 to 40 percent are also on anti-seizure medications.

*Risks:* Some children and adults with autism may become combative or may run away under extreme stress.

*Physical attributes:* No difference structurally; may manifest unusual motor behaviors, eg. Flapping, flicking, chewing, covering ears, etc. (\*Fragile X). May have identifying bracelet, necklace, or shoe tag.

Cognition: Intelligence ranges from extremely intelligent to severely mentally retarded with 70-80% in retarded range. Girls usually have cognitive limitations. Some individuals with autism have "savant" skills; usually in math, science, music, or art.

Communication: The ability to communicate in these individuals ranges from good expressive and receptive language to non-verbal with little or no receptive language. Many individuals with ASD have been exposed to sign language or icons regardless of whether they are verbal or non-verbal. Even very bright, verbal individuals are usually very concrete in understanding of language and under stress may have difficulty understanding or expressing language; therefore, an icon or written word is more effective than speaking.

• *Diagnosis:* Mental Retardation or Developmental Delay, is defined as sub-average intellectual ability as well as poor social adaptation. May or may not manifest physical abnormalities. May be part of a syndrome such as Down syndrome or Fragile X syndrome.

*Cause:* Both heredity and environment contribute to intelligence. The cause is unknown in most cases unless the mental retardation is part of a syndrome. Most syndromes are genetic in nature. Some are exacerbated by difficult births, environmental toxins, etc.

*Incidence:* Approximately 3 percent of the total population is mentally retarded. Some syndromes are decreasing as a result of genetic counseling, neo-natal treatment, etc. Down syndrome occurs in 1 of 700 newborns.

*Medications:* Many individuals with mental retardation take seizure medications. Some are on anti-anxiety drugs or thyroid medications.

*Risks:* Under stress may become combative (fight or flight response) due to impulsivity and concrete thinking. Many have seizure disorders, cardiac problems, etc. Approximately 35 percent of individuals with Down syndrome have heart defects and are at greater risk for leukemia.

*Physical Attributes:* May have distinct facial features (as in Down syndrome and William's syndrome) and/or physical anomalies. Individuals with Down syndrome have hypotonia, small head, and large protruding tongue; may have problems with both speaking and swallowing.

*Cognition:* By definition, at least some intellectual differences, Mental retardation ranges from mild retardation (an IQ of 52-68) to profoundly retarded (an IQ of 19 or below). Usually, somewhat concrete in thinking. The average intelligence quotient (IQ) in an individual with Down syndrome is about 50.

*Communication:* Varies from adequate speech and language to sign language or recognizing icons. These individuals are usually very concrete in their understanding of language. Communication should be simple with no use of metaphors or similes.

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## III. <u>PSYCHO-SOCIAL DISABILITIES</u>

There are many psycho-social disabilities listed in the DSM-4 including individuals who have mild to moderate problems with communication depending on current status (chronic vs acute) and medication. Only those disabilities requiring alternative communication will be discussed.

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# • Diagnosis: Schizophrenia

Schizophrenia is a mental illness characterized by thought disorders and hallucinations.

*Cause:* Currently, this disorder is though to be genetic in nature. Stress may be the factor that initiates the onset of this disorder in early adulthood.

#### Incidence:

*Medication:* Most individuals who are receiving medical treatment for this disorder are on a variety of medications including psychotropic drugs, etc.

Risks: May become combative under stress.

*Physical attributes:* No difference structurally; may manifest unusual motor behaviors, eg. Flapping, flicking, chewing, covering ears, hearing voices, etc. May have identifying bracelet, necklace, or shoe tag.

*Cognition:* Intelligence range is same for general population; however, medications may affect cognition.

*Communication:* The ability to communicate in these individuals ranges from good to extremely difficulty due to medications, hallucinations, etc.

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# IV. <u>LEARNING DISABILITIES</u>

Learning disabilities may be specific or general in nature. Often, difficulties with learning are concomitant with other disorders. Severity ranges from severe to mild in both children and adults. Many children and adults with normal range intelligence have difficulties with receptive and expressive language. Only those learning disabilities that require alternative communication strategies will be presented.

• *Diagnosis:* Severe disorder of language

*Cause:* Etiology unknown, however there may be strong familial incidence. Many developmental and neurological conditions have concomitant language processing difficulties.

*Incidence:* Difficult to estimate due to overlap of other areas of dysfunction.

*Course:* usually, caretakers recognize severe language disorders during the first and second year of life when language first develops. Some individuals have excellent receptive language and extremely limited expressive language. In children, behavior is often adversely affected due to frustration and inability to express wants and needs from caretakers. In addition to language processing problems, individuals may have additional learning disabilities.

*Physical attributes:* In most cases (except syndromes) individuals with learning difficulties and communication disorders are no different than the general population.

Cognition: By definition, a learning-disabled person must have within normal range intelligence. Overall, intelligence ranges from very intelligent to low normal. Individuals with severe communication disorders may have limited intellectual functioning.

Communication:	Most	learnin	g-disabled	individuals	are	able	to u	understan	id and	express
information nece	essary	under	emergency	/ situations.	Ind	ividual	ls w	ith mode	erate to	severe
receptive and ex	pressiv	e langu	iage difficu	lties may us	e sig	n lang	uage	e, icons, o	or augr	nentative
communication d	evices.									

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This program, COMMUNICATING WITH INDIVIDUALS WHO HAVE VARIOUS DISABILTIES THAT MAY BE ADVERSELY AFFECTING COMMUNICATION includes this manual, a communication booklet, posters and an accompanying video. It is meant to be a brief introduction to the topic. For further information, please refer to the references following this page or contact a local, state, or federal program that assists individuals with disabilities.

# **Bibliography**

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For more information on autoimmune related diseases, see <a href="www.aarda.org">www.aarda.org</a>.