Include Autism Presents:
The volunteer Handbook
The volunteer Handbook:
Working With People Who Have An Autism Spectrum Disorder

Brought to you by:
Include Autism

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Introduction

With gratitude and enthusiasm we welcome you to Volunteering With People Who Have an Autism Spectrum Disorder! As a Peer Pal or a Volunteer you have the opportunity to make a difference in the lives of individuals with autism, while supporting the mission of promoting awareness and inclusion in the community.

Most volunteering programs exist to provide first-hand experience with and support to individuals with autism, while serving as a positive role model and friend. The gift of your time, friendship, hard work and encouragement engenders a sense of self and community engagement in programs throughout our communities. As they become familiar with you and you with them, the opportunities to promote inclusion and friendship only deepen.

The purpose of this handbook is to provide basic information about autism, and direct service volunteer programs. I hope you will find your experience rewarding and meaningful.

Thank you - you truly make a difference.

Autism Is...

According to Autism Speaks, autism is a complex neurobiological disorder that typically lasts throughout a person’s lifetime. It is part of a group of disorders known as autism spectrum disorders (ASD). It occurs in all racial, ethnic, and social groups and is four times more likely to strike boys than girls. Autism impairs a person’s ability to communicate and relate to others. It is also associated with rigid routines and repetitive behaviors, such as obsessively arranging objects or following very specific routines. Symptoms can range from very mild to quite severe.

Prevalence

According to the Autism Society of America and the Program for Disease Control (CDC), the prevalence of autism has risen to 1 in every 88 American children. Recent studies report that ASD prevalence was 4 to 5 times higher for boys than for girls and occurs in all racial, ethnic and social groups. These estimates typically include those with autism, Aspergers Syndrome, and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) as considered part of Autism Spectrum Disorder.
By the Numbers

Autism Diagnosis Rates
1980: 1 in 5000
1990: 1 in 1000
2000: 1 in 500
2007: 1 in 150
2010: 1 in 110
2012: 1 in 88

By the numbers
1%: U.S. children with autism spectrum disorders
3: Average age for diagnosis
40%: Children with autism who do not talk
$35 billion: Annual spending on caring for people with autism
$3.2 million: Amount spent caring for each person with autism over their lifetime

SOURCES: Programs for Disease Control and Prevention; Harvard University School of Public Health

Characteristics & Symptoms

In the first few years of life, some toddlers with autism reach developmental milestones, such as talking, crawling, and walking, much earlier than the average child; whereas others are considerably delayed. Approximately one-half of autistic children develop what appears to be typically often until around 1 1/2 to 3 years of age; then autistic symptoms begin to emerge. However, many parents of children with autism state that they noticed symptoms earlier but were not aware that they may have been caused by their child’s autism.

"WHEN YOU KNOW ONE PERSON WITH AUTISM,
YOU KNOW ONE PERSON WITH AUTISM."

The strengths and deficits of this disorder show up differently in each individual. The following challenges, however, are present in each of our program participants:

Deficits in social interactions and relationships such as significant problems developing nonverbal communication skills, like eye-to-eye gazing, facial expressions and body posture; difficulty establishing friendships with children the same age, and lack of interest in sharing enjoyment, interests, or achievements with other people.
Verbal and nonverbal communication such as delay in, or lack of, learning to talk, problems taking steps to initiate and maintain conversation, stereotyped and repetitive use of language, echolalia, or difficulty understanding their listener’s perspective.

Self-stimulatory behaviors such as repetitive, non-goal directed behavior; this looks like rocking, hand-flapping, self-injury (e.g., hand-biting, head banging), sleeping and eating problems, poor eye contact, insensitivity to pain, hyper-/hypo-activity, and attention deficits. Also known as “Stimming”

"Perseverative" behaviors such as becoming overly insistent on routines; if one is changed, even slightly, the child may become upset and tantrum. A perseverative behavior may also be a self-stimulatory behavior.

Limited interests or specialized interests in activities or play such as unusual focus on pieces of a game or parts of toys (the wheels on a car rather the entire toy), or a preoccupation with certain topics. For example, older children and adults may be fascinated by video games, trading cards, or license plates.

* Factors such as age, both chronological and developmental, as well as characteristics of individual personalities also play a part in how a program participant’s individual proficiencies and challenges manifest.

Sensory Integration Issues

Many if not all individuals with autism seem to have an impairment or disregulation with one or more of their senses. This impairment can involve the auditory (hearing), visual, tactile (touch/pressure), gustatory (taste), vestibular (equilibrium/balance), olfactory (smell), and proprioceptive (motor planning/body’s relationship to space) senses.

Hyper Sensitivity: over-responsive or acute, causing painful responses to “normal” stimuli, over responsive, giving the brain little too much or an “overload” of information with which to interpret and respond to the environment.

Hypo Sensitivity: under responsive, giving the brain little to no information with which to interpret and respond to the environment.
Cognition

“Theory of mind” refers to one’s inability to realize that other people have their own unique point of view about the world. Many autistic individuals do not realize that others may have different thoughts, plans, and perspectives than their own. For example, a child may be asked to show a photograph of an animal to another child. Rather than turning the picture around to face the other child, the autistic child may, instead, show the back of the photograph. In this example, the autistic child can view the picture but does not realize that the other child has a different perspective or point of view.

Many individuals with autism also have a narrow or focused attention span; this has been termed ‘stimulus overselectivity.’ Basically, their attention is focused on only one, often irrelevant, aspect of an object. For example, they may focus on the color of a utensil, and ignore other aspects such as the shape. In this case, it may be difficult for a child to discriminate between a fork and a spoon if he/she attends only to the color. Since attention is the first stage in processing information, failure to attend to the relevant aspects of an object or person may limit one’s ability to learn about objects and people in one’s environment.

Causes

Although there is no known unique cause of autism, there is growing evidence that autism may be linked to a variety of factors which may include, but not limited to:

- Genetics
- Environmental exposures to toxins and pollutants
- Exposure to viruses or diseases
Best Practices in Communicating With Someone With Autism

- Use a clear, calm voice
- Don’t raise your voice especially if someone is upset
- Give short, precise directions and sentences
- Be consistent and concrete when giving directions/instructions
- Wait a minimum three seconds between repeating a direction

Ask Questions to ask staff and support:

What are my partner’s interests?

What is he/she working for today? (Is the reward a match for their interests?)

What will our environment be like? Is there anything to watch out for?

How does my partner communicate most comfortably?

Does my partner need a visual aid or written schedule?

Is there anything in particular that my partner does NOT like?
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