Autism

by Helena Haddad, R.N., C.D.D.N.

Autism is the most common condition in a group of developmental disorders known as the autism spectrum disorders (autism, Asperger’s disorder, childhood disintegrative disorder, Rett’s syndrome and pervasive developmental disorder-not otherwise specified). It is now estimated that one in every 166 American children has a diagnosis of autism. The recent dramatic increase in cases has expanded the demand for more funding for research into prevention and treatment.

Autism or "classical autism" is defined as a complex non-progressive developmental disability. Symptoms usually appear before the age of three years and can vary in their complexity and severity. Before the formal diagnosis, many parents noted that although their toddler met all of their milestones, something was different. During infancy, the baby was fussier, not as cuddly and more difficult to feed than his/her siblings. Usually by an infant’s third birthday parents are concerned enough to seek help.

The triad of classical symptoms is: impaired development of social interactions, impaired development of communication and a restricted repertoire of activities and interests. A fairly typical scenario is a toddler who does not want or seek out social interactions, has an obsessive interest in only a few toys or objects, eats only certain
food presented in a certain manner, is non-verbal and is very resistant to changes in routine. These traits make transitioning into traditional learning programs nearly impossible.

A complex disorder, autism is diagnosed by observation and screening instruments administered by learning and developmental specialists. There is no definitive test (blood, scan, DNA, etc.) that can diagnose it. Infants may first be misdiagnosed as having a hearing impairment because of their indifference to their surroundings. Children who are mildly affected may not be diagnosed until after they enter school. Boys are four times more likely to be diagnosed with autism than girls. All races and socioeconomic groups seem to be affected equally. Recent studies strongly suggest that autism may have a genetic component. Parents with one child with autism have a one-in-20 chance of having a second child with the disorder. There is also a link among families that have members with emotional disorders, such as bipolar disorder.*

There is no treatment for autism that cures the disorder. The most widely accepted treatment is intense behavioral therapies and interventions for specific symptoms such as impaired social interactions. Interventions and therapies introduced very early are believed by many parents to have made a significant difference in allowing their child to live a more normal life. Like any disorder, some symptoms may become less significant as the child ages and others may become more pronounced. Also, many children have a co-existing disorder, such as epilepsy, cerebral palsy or mental retardation that makes management more complicated.

Use of medications is controversial except to manage symptoms of a co-existing disorder, such as a mental illness or epilepsy. An Internet search for autism treatments results in literally thousands of "hits" related to this subject. Many include vitamin and dietary supplement therapy that offers a "cure." Parents may become very confused as to what to do for their child. The best advice a nurse can give parents is to seek input from trusted and reputable sources such as the child’s pediatrician, school counselor or an autism support group.
Asperger’s Disorder

Asperger’s disorder is an autism spectrum disorder. It has specific diagnostic criteria, which are outlined in American Psychiatric Association’s Diagnostic & Statistical Manual of Mental Disorders (DSM-IV-TR). Autism and Asperger’s were once considered to be the same disorder with different levels of severity, Asperger’s being less severe. Currently they are considered two different but closely related disorders.

Persons with Asperger’s disorder usually have normal or high intelligence and develop speech normally. Many excel in school in a specific subject but have significant difficulties in others. Their interests are narrow and may border on compulsive. Interpersonal relationships are difficult because they appear socially awkward and can’t read body language, gestures and facial expression of others. Persons with Asperger’s have difficulty with abstract thinking and concepts, lack empathy and seem indifferent to the feelings of others. Some individuals may not develop enough life skills to be able to live alone. Others may go on have successful careers and personal lives.

When nurses interact with persons with autism or Asperger’s in community settings, they must allow plenty of time to complete nursing tasks. During the first meeting, the nurse may only have the opportunity for an introduction. Further appointment(s) may have to be set up to do the actual nursing task. Making a house call is less traumatic than having the individual come to a busy clinic. Allowing the person to hold a familiar object and have a favorite caregiver or family member nearby will be reassuring. Explaining what will happen in simple, concrete terms will benefit most individuals. Sometimes explaining to the caregiver first allows the caregiver to translate terms that the individual best understands. A person with Asperger’s may want a detailed explanation that includes holding or touching the equipment before they consent to an exam. Demonstrating the task on the caregiver will also help. On rare occasions, a person with autism may be so frightened that he/she will need a sedative prior to the appointment. Coordinating appointments can save the person from receiving multiple sedations.

A diagnosis of autism or Asperger’s does not make the individual more at risk for contracting illnesses. Most are healthy and only need routine health surveillance. However, because their communication skills may be limited, it is often difficult to determine when they are having pain or other symptoms. Fractures and dental pain may be overlooked for lack of objective evidence. Caregivers and family members usually know when the individual is not feeling well by a change in sleep pattern, appetite or activity level. Nurses who care for individuals with autism and Asperger’s usually find the interactions challenging but very rewarding and fulfilling.

*Editor’s Note: There are a number of theories regarding the cause(s) of autism including speculation that vaccines or thimerosal cause autism however; there is no scientific evidence to support these theories. The Centers of Disease Control and Prevention’s (CDC) Centers for Autism and Developmental Disabilities Surveillance and Epidemiology (CADDRE) are working on large scale population-based studies to look at possible factors or causes of autism and possible prevention strategies. For more information go to www.cdc.gov/ncbddd/autism.
Medical malpractice

An opinion by Bernadette Murphy, R.N.

I had the pleasure of recently serving on a jury for six days in a medical malpractice case. The plaintiff went in for a minor, non-invasive procedure and things went terribly wrong. Even though we found for the plaintiff, all of the jury members agreed no one could be considered a “winner” in this case. The plaintiff was harmed and will have to endure future pain and possible surgery; and the physician, who we all agreed for the most part was a good doctor, now has a mark of negligence on her record.

Following the procedure when the plaintiff returned to post-op, her recovery deteriorated as evidenced by her pain levels going from 2/10 to 8/10, 9/10 and finally 10/10. While she had received a total of 3,000cc of IV fluids after the procedure her output was only 50cc’s of dark amber urine. Pain medications were atypical (morphine and Demerol) for a minor, non-invasive procedure. She was sent home, only to return to the emergency room 14 hours later.

What surprised me the most was the lack of documentation by the nursing staff. In all of the nurses’ notes there was nothing that documented the source of the pain, or any measures that were tried besides medication to address the pain, nor was there an assessment of the plaintiff’s physical condition — even of the area where the procedure was performed!

On the witness stand, each time the prosecutor asked the various nurses who cared for the plaintiff what care and services they provided they all looked at copies of the chart notes, only to find that there was nothing there. “I don’t know” and “I can’t remember” were phrases that rang hollow to me and the other jurors; the nurses’ credibility was greatly damaged.

As the nurse on the jury, people would ask me, “Aren’t nurses supposed to write these things down?” “If they didn’t document it, how do we know it was done?” “If the nurses did do a good job of caring for the plaintiff, why didn’t they write it down?” Knowing the importance of good documentation, I could only answer that their questions were valid, and the same ones that I had. You don’t have to have any medical training to know that when lots of fluids are going in and very little is coming out or someone’s pain is 10/10,
the nurses should be doing data collecting and assessing, and then documenting what they have done, what they have found, and to whom it was communicated.

The nurses in this case allowed themselves to be limited by the forms they were using. Once the preprinted lines and boxes were filled up documentation stopped. The only problem is that the patient’s recovery/deterioration process did not.

At the beginning of this article I mentioned the fact that neither the plaintiff nor the defendant, were winners in this trial. Additionally, the nurses lost, because their credibility (to themselves, and therefore to their employer) was damaged. The jurors, myself included, stated many times “I’ll never go to _____ to have anything done if their nursing care is like that.” By allowing themselves to be limited by a few preprinted lines, by not assessing the patient and taking prudent action on the data they collected and then by not documenting what care and services they did provide, the nurses made themselves the third victim in this trial.

I hope this experience serves as a reminder to nurses everywhere the importance of documentation; not just filling out forms but complete, accurate, and thorough documentation. What you document now may be the only memory you have in the future. I had an instructor in nursing school who used to always say, “Document as if you were going to go to court.” Her point became very clear to me after this experience.

Bernadette Murphy, R.N., is the health education training coordinator with the DHS Seniors and People with Disabilities Division.
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# 32nd Annual Oregon State University Gerontology Conference April 3 & 4, 2008

Over 40 educational sessions will be presented by leading geriatric professionals at this year’s OSU Gerontology Conference. Our conference theme for 2008 is “Active Approaches to Healthy Aging”. Featured topics cover: end-of-life care, physical activity, mental health, healthy aging, cultural competency, and more!

A broad array of sessions will be offered, such as:

**Use it or Lose it: How to Create an Effective Cognitive Enhancement Program**  
*Robert Winningham, PhD*, Associate Professor of Psychology, Western Oregon University, Monmouth, OR.

**Making Progress Toward Aging Well: Description, Impact, and Outcomes From a Faith Community-Based Health Promotion Program**  
*James White, PhD*, Assistant Professor, Bemidji State University, Bemidji, MN.

**Future Seniors: Who Are We? How Do We Differ From Today’s Senior? Are You Ready?**  
*Clara Pratt, PhD*, Emeritus Faculty, Oregon State University, Corvallis, OR.

**Physical Activity: It’s Role in Successful Aging and Chronic Disease Management**  
*Elizabeth Eckstrom, MD, MPH*, Associate Professor, Oregon Health & Science University, Portland, OR.

**Moving From Awareness to Action: A Community Approach Towards Reducing Elder Suicide**  
*John Cascamo, MS*, Assistant Dean, Klamath Community College, Klamath Falls, OR.

For information on additional sessions or to register, please visit our website:  
[www.osugero.org](http://www.osugero.org)

For assistance, call 541-737-0954 or email brandi.hall@oregonstate.edu

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**Sponsored by** Oregon State University (OSU) Extension Family and Community Development, OSU Program on Gerontology, OSU College of Health & Human Sciences, Oregon Geriatric Education Center, Samaritan Health Services, & Cascades West Council of Governments.
Long term care providers recognized:
Clatsop Care Center, Emerson House and Mennonite Home

Three long-term care providers in Oregon have been named Innovative Practice Champions by the Surveyor Provider Forum.

The providers honored are Clatsop Care Center, a nursing facility in Astoria; Emerson House, a residential care facility in Portland; and Mennonite Home, a nursing home in Albany. They received certificates from DHS Seniors and People with Disabilities Division (SPD), and were honored at the Oregon Health Care Association’s annual convention in Portland and the Alliance of Senior and Health Services’ conference in Newport last fall.

The Surveyor Provider Forum, a group of surveyors, providers and provider trade organization representatives, designed its first Innovative Practices Program in 2007 and issued a call for applications from long term care providers in licensed assisted living, residential care and nursing facilities.

The Innovative Practice Program grew out of the forum’s desire to share quality practices. Its aim is to recognize providers who have taken initiative to design and implement inventive and innovative practices, and who share their successes and experiences for the benefit of residents, staff, families and regulators.

The program’s formal goals are to:

1. Identify providers who illustrate creativity and commitment to quality through a selected area of care, program or service, and

2. Formally recognize those providers who deliver exemplary care or services to their peers, surveyors and customers.

The area of care selected for the 2007 Innovative Practice Program was activity or life-enrichment programs.
The applications were reviewed by a diverse committee with representatives from the provider trade organizations, DHS, Making Oregon Vital for Elders (Oregon’s culture change coalition), academia, activity professionals, private consultant, the office of the Long Term Care Ombudsman and the Oregon Gerontological Association. The reviewers used a set of criteria identified by a work group from the Surveyor Provider Forum. Applications were evaluated individually against the criteria rather than against one another.

The Surveyor Provider Forum was formed in 2005 and is convened by SPD’s Office of Licensing and Quality of Care. Forum membership is voluntary and requires an attendance commitment of a minimum of one year.

Preventing and responding to financial abuse

In September 2007 Mary Doan pleaded guilty to stealing blank checks from an ailing older adult to whom she provided in-home care.

Ann Bishop was supposed to take care of a woman with Multiple Sclerosis who needed help with eating, dressing and bathing. Instead, she stole checks and bank account information to get cash, pay bills and buy pre-paid phone cards. In all, $1,717 was taken from the client’s accounts.

Before he succumbed to lung cancer, Vic Jackson had grown suspicious of his home health aide. He wanted to take care of the situation himself, but he was too sick to act. By the time Vic died, the care giver had stolen $275,000.

Nationally and in Oregon financial exploitation has become the major category of perpetrator-related abuse.

Adult Protective Services in Oregon defines financial abuse as the illegal or improper use of an elderly person’s funds, property or assets. There are many forms of financial abuse. The bottom line is that someone tries to get money, property and belongings (including medications) from unsuspecting and vulnerable adults. Financial abuse means that someone is misusing or stealing the resources of an older person or person with disabilities for the abuser’s own personal or monetary benefit.

How would I know if a client was being financially exploited?

As people grow older or incur disabilities, many rely on others for services, including help with their finances. Often financial exploitation goes hand-in-hand with other types of abuse and neglect. If you see that
As a nurse, you may be one of the few contacts that your client has with the outside world. You may know someone who is vulnerable and at risk because they are isolated and lonely. Perhaps they do not have family members or other individuals who can help look out for them. They may have become confused and forgetful about things like money, or they may appear to tolerate exploitation in exchange for companionship or assistance. This can be a result of undue influence, threats or lack of information about other options. These are common risk factors and as a health care professional you may be able to prevent further abuse by being aware of the warning signs.

Common warning signs of financial abuse

- Frequent gifts from an elder to a care giver.
- Bills start to stack up and are not paid, often leading to shut-off notices.
- A recent will is made when the person doesn’t seem capable of writing a will.
- A care giver’s name is added to the bank account or credit cards.
- Care giver refuses to spend money on the older person, including grooming items and food.
- Care giver is spending an excessive amount on new clothing, jewelry, automobiles and other items for him or herself.
- Care giver is gambling.
- Power of attorney is given, or there are changes in a will or trust when the person is incapable of making such decisions.
- The elderly person is missing personal belongings such as art, silverware or jewelry.
- Medications with high street value are missing or unaccounted for.

Mandatory reporting

Licensed nurses are mandatory reporters of suspected abuse. Under Oregon law, any reporter of elder abuse has immunity from civil liability for making a report in good faith and participating in any judicial proceeding resulting from the report. The identity of the person making a report of elder abuse is confidential. However, if there is a criminal investigation, law enforcement may have the name of the complainant and the name can be disclosed by judicial process.

Making a report

Suspected financial exploitation is investigated by the local Seniors and People with Disabilities office in your area. To find the local office in your area, go to the DHS Web site: www.oregon.gov/DHS/localoffices or call the DHS state office at 1-800-232-3020.

Adult Protective Services (APS) regularly intervenes in exploitation involving personal relationships. The suspected exploiter is most often someone known by the victim. It may be family, a friend, care giver, legal
fiduciary or acquaintance. Older adults are particularly vulnerable to abuse from persons they know, trust, love or depend on. APS staff are experienced in dealing with the delicate nature of abuse by a family member or someone close to the adult.

Services

Services offered to the older adult can include, but are not limited to: advocacy, assistance with referrals for financial, legal, housing and medical needs. Money management and other options may be offered if resources are available. If a crime has been committed, the APS agency will work with law enforcement and the district attorney’s office on possible prosecution and restitution. Civil action may also be initiated.

Protection

Stan Wilson’s nurse became concerned when she attempted to call Mr. Wilson to set up her visit and learned that his telephone had been shut off. Upon arrival she observed envelopes marked “Past Due” that were left unopened on the floor and that an eviction notice had been posted. She also noticed his daughter visiting more frequently but leaving whenever the nurse arrived. The nurse called Adult Protective Services.

APS staff needed the help of the maintenance staff to enter Mr. Wilson’s apartment. They found him alone, weak and confused, wearing soiled clothing and with little evidence of food supplies. He was not able to understand the eviction notice or other bills that lay unopened.

With the help of APS and community resources a representative payee was appointed for Mr. Wilson. His rent, PGE and telephone bills were paid. In addition an AARP medical plan was set up and Mr. Wilson was still able to control his small pension check for spending money. A food box, some clothing and other household items were donated to him.

His daughter voiced objections to her loss of access to her father’s accounts. She subsequently went to jail and is required to complete drug treatment.

You can be a part of a success story like this, by being alert to the signs of potential abuse and contacting your local APS office for help. For more information, contact your local office, or review additional resource materials at: preventelderabuse.org.
New Individual Support Plan training targets registered nurses

A live online training session on the Individual Support Plan will be held on Wednesday, February 27.

This free training session, designed to meet nurses' busy schedules, is highly recommended for all RNs who provide nursing services to persons with disabilities and who use Oregon's comprehensive ISP process. It is also recommended for other team members who work with RNs, including house and program managers, vocational/ATE supervisors, executive directors, clinical doctors and CDDP staff.

Presenters are Alan Lytle of Oregon Technical Assistance Corp. (OTAC) and Terry Rittner, R.N., of the DD Licensing unit of DHS Seniors and People with Disabilities Division's Office of Licensing and Quality of Care. They will present information about Oregon’s ISP process that is specifically relevant to individuals who receive direct nursing services.

Topics to be covered include understanding and contributing to the PFW, RTR, Support Documents, and ISP within the context of the nursing assessment and nursing care plan.

A broadband (DSL or faster) Internet connection is required to participate. All participants must pre-register at least 24 hours in advance through OTAC’s Web site. Registrants will receive instructions via e-mail for logging on to the Webinar.

Please contact OTAC at www.otac.org/isppipeline or alytle@otac.org for more information and to register.
Continuing education for community-based nurses

The office of Licensing and Quality of Care is pleased to announce its first self-study continuing education course for community-based nurses. The course, “Self-directed learning series: Registered Nurse Delegation in Oregon,” is available at no charge for download at the DHS Web site www.oregon.gov/DHS/spd/provtools/nursing/. You can also e-mail your request for the course to CRNHSU@state.or.us.

Upon completion of the course you can apply for 2.0 contact hours of nursing continuing education (CE). The cost of CE hours is $20. Instructions to apply for CE hours are contained in the self-study course. Thanks in advance to those who take the time to complete this RN Delegation self-study course, which demonstrates your commitment to professional nursing excellence within Oregon’s long-term care system.

A survey will be sent to SPD Contract RNs to determine their training needs regarding non-traditional health related issues. If you don’t receive a survey by the end of February, please contact Bernadette Murphy at Bernadette.J.Murphy@state.or.us.