Being Aware: Subtle signs and symptoms of illness or injury in persons with Intellectual and Developmental Disabilities (I/DD)

These may be a sign of illness or injury:
Look for any change from the individual’s usual state or behavior. This could include any of the following:
• Difference in crying or moaning
• Self-stimulation or rocking
• Agitation, hurting others or self (This is a common response to pain or illness.)
• Fatigue/Sleepiness/Lethargy
• Difficulty sleeping
• Less alert than usual; active or confused
• Less able to do usual things
• Greyish/bluish lip color or nails
• Rash, blisters, growths, lumps
• Difficulty chewing/swallowing
• Eating more or less than usual
• Difficulty breathing or new coughing
• Unsteadiness, leaning, falling
• Swelling of feet or ankles
• Trembling or losing consciousness
• Loss of vision or hearing
• Decline or loss of mobility
• Refusing to eat or drink
• Sudden stomach pain
• Weight loss or gain
• More or less incontinence
• Change in urine or bowel movements
• Increased seizure activity

Remember:
• Observe closely and note any changes.
• Communicate quickly and clearly!
• Notify your agency nurse of changes.
• Document what you see (or don’t see!)
• Take prompt action: Prompt treatment may save his/her life!
• Call your Regional Office Nurse or Clinical Services Bureau for assistance or consultation at any time. See phone numbers listed below.

This DDSD Health Alert is intended to remind provider staff at all levels to quickly recognize changes and to promptly obtain health services for individuals in order to quickly treat illness or injury and to minimize pain, decline in function or even death from unrecognized or untreated illnesses or injuries. Please share this document with direct care staff and other staff within your organization. Use this information in training as needed.

When adults begin to get sick, the illness can present in a variety of ways. Most adults experience and present typical or expected signs of a condition or illness with signs such as fever, coughing, fatigue or pain.

Many individuals with I/DD are able to communicate when they feel ill and do show typical or expected signs of illness. However, some individuals may not be able to tell you they are ill and it is important that you pay close attention to any observable signs of illness or injury, that is, changes in an individual’s normal status. These are also called “Subtle Signs” of illness or injury. These may occur when someone is having problems with pain, a medication, has an infection, constipation, dehydration, aspiration or a major illness or health event.

Signs of illness and injury can appear quickly within hours or days of a condition or an illness and most typically continue to worsen over time. That is why early detection and treatment are so important.

A list of possible subtle signs is provided at the left. It is not all-inclusive since every person is unique.

Health care and medical emergency response plans should describe each person’s unique observable signs of illness. All staff should receive individual specific training on recognizing the observable signs.

Prompt action means seeking medical attention by calling the individual’s nurse to get an assessment or direction, making sure they are closely watched and taken to their Primary Care Practitioner (PCP), Urgent Care or the Emergency Room as needed.