

About 15% of children with Down syndrome have **atlantoaxial instability**; almost all of the children are asymptomatic. The American Academy of Pediatrics no longer recommends screening asymptomatic children with Down syndrome for atlantoaxial instability with cervical spine x-rays due to unproven value of detecting patients at risk of developing spinal cord compression injury ([Bull and Committee on Genetics, 2011](#); [National Down Syndrome Society, 2012d](#)). However, the Special Olympics continues to require that all athletes with Down syndrome receive neck x-rays prior to sports participation, because neck x-ray is the only screen available ([National Down Syndrome Society, 2012d](#)).

### **Nursing Alert**

Immediately report any child with the following signs of spinal cord compression:

- Persistent neck pain
- Loss of established motor skills and bladder or bowel control
- Changes in sensation

### **Prognosis**

Life expectancy for those with Down syndrome has improved in recent years but remains lower than for the general population. The majority of individuals with Down syndrome survive to 60 years old and beyond ([National Down Syndrome Society, 2012e](#); [Weijerman and de Winter, 2010](#)). As the prognosis continues to improve for these individuals, it will be important to provide for their long-term health care and social and leisure needs.

### **Nursing Care Management**

#### **Support the Family at the Time of Diagnosis**

Because of the unique physical characteristics, infants with Down syndrome are usually diagnosed at birth, and parents should be informed of the diagnosis at this time. Most parents usually prefer that both of them be present during the informing interview so that