

[Date]

To whom it may concern:

[Add individual’s name with AS] carries a diagnosis of Angelman syndrome. Angelman syndrome (AS) is a rare neuro-genetic disorder that occurs in one in 15,000 live births or 500,000 people worldwide. It is caused by a loss of function of the UBE3A gene in the 15th chromosome derived from the mother. Angelman syndrome shares symptoms and characteristics with other disorders including autism, cerebral palsy and Prader-Willi syndrome. Due to the common characteristics, misdiagnosis occurs often. People with AS have developmental problems that become noticeable by the age of 6 – 12 months. Other common signs and symptoms usually appear in early childhood like walking and balance disorders, gastrointestinal issues, seizures and little to no speech. Despite these symptoms, people with Angelman syndrome have an overall happy and excitable demeanor. An individual with AS will light up a room with their smile and laughter.

[Add individual’s name with AS] has a history or the ability of eloping and running away from safe environments such as [his/her] home. Recently, an individual with AS left his home after opening multiple doors and went across a busy street where he could have been hit by a car and then was difficult for the family to locate. It is obvious that an individual with the above list of problems who leaves a safe environment on his own and wanders in the community will encounter harmful and potentially life-threatening situations, which makes this an important safety issue for [Add individual’s name with AS] and [his/her] family and caregivers. We find that it is medically necessary for this individual to have a safety bed to prevent harm.

Due to the nature of [his/her] condition, [Add individual’s name with AS] will wander from safe environments. [Add individual’s name with AS]’s wandering tendencies include goal-orientated elopement, which means [he/she] will leave the home and seek out places or items of interest, which includes the entire outside world and even more dangerous, water.

To ensure [Add individual’s name with AS]’s safety, it is medically necessary that family and caregivers responsible for [his/her] safety and well-being utilize some form of safety bed. This is a generally accepted form of safety for individuals who have the possibility of harming themselves if not enclosed. A bed should be safe, secure and comfortable, and going to bed at night should bring rest rather than danger. But for some parents of children with special needs, bedtime can feel like an obstacle course with many difficulties to overcome each night. Safety beds or Adaptive Beds all share a common goal of keeping the user safe from falling out or injuring themselves as a result of being in bed. To qualify as a safety bed, a bed must address four specific issues:

1. It must protect from falls. There must be something built into the bed that keeps the user from falling out, not just while sleeping, but while awake and moving about.
2. It must prevent unassisted exits. An individual should not be able to engage the mechanism that allows exit from the safety bed, either on purpose or by accident. Many children can injure themselves getting out of bed, and of course, can wander and harm themselves once out of bed.
3. It must be easy to open. Cumbersome or difficult unlocking mechanisms have no place in a safety bed. A parent must be able to open the bed quickly and easily with one hand and assist or control the child with the other.
4. It must protect from entanglement or entrapment. Statistics tell us that when a person becomes entrapped in bed rails, injury results nearly 77% of the time, and 59% can even die as a result. Safety beds absolutely must be safe, eliminating any risk of entrapment.

We strongly recommend a safe sleeping environment for [Add individual’s name with AS] because without it, [he/she] would severely injure [himself/herself]. It will also ensure [he/she] has a safe and secure sleep environment which will provide the restorative sleep that [he/she] needs and peace for the family. It is essential that insurance cover this cost for the family as the burden of the expense can add stress to the caregiver.

Sincerely,

Clinicians of the Angelman Syndrome Clinical Research Network

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