

**Sample Letters from Parents/Eligibility and Priority Category:**

**Eligibility Letter of Support from Parent: Jack**

Jack has a genetic disorder called \_\_\_\_, which may be a form of Autism. The syndrome causes severe physical and intellectual disabilities. Jack has virtually no language skills, very limited fine movements, has a strange walking gait, and has a number of behaviors related to Autism. Jack needs direct hands-on assistance with all activities of daily living. He needs supervision and physical assistance with all recreational activities. He is ambulatory and needs constant supervision, redirection and intervention.

Jack was seriously ill at birth. His body weight was just under three pounds and his gestational age was 32 weeks. Significant problems included Hyaline membrane disease, patent ductus arteriosus, severe pulmonary edema, hemolytic anemia, and very low muscle tone. After two months in the neonatal ICU, Jack came home on oxygen therapy because of bronchopulmonary dysplasia. He required nasal-gastric feeding, electrolytes, a diuretic, an anticonvulsant, and thyroid hormone.

When Jack was young, he received intensive physical, oromotor, and occupational therapies in the home, at school and privately. He attends \_\_\_\_ County Public School (Multiply Handicapped, Intensity 5).

Jack has a long history of feeding disorders. As an infant he took nutrition by machine day and night. Eventually he had surgery and a gastric tube. Eventually he learned to chew and swallow. He eats by mouth now, but he cannot feed himself with utensils because of his poor motor skills. Jack has always been sensitive to the heat and cold. When he gets sick, he spikes a very high fever. When he gets out of a shower, he has to be dried off quickly or he shivers excessively.

Jack now has excellent upper limb strength though he otherwise has poor muscle tone and poor motor skills. Jack uses his arm strength to prevent falls and manage doors and other large objects without the benefit of more coordinated movements. His skill learning is very slow. Jack can learn a new skill with lots of practice, but only if he is highly motivated. He has difficulty using old skills for new problems. This is evident when Jack tries to open a door or flush a toilet with an unfamiliar handle. Each new physical arrangement must be learned separately. If he does not keep practicing a learned skill, it can disappear.

Though he was unable to walk until he was six years old due to poor muscle tone, Jack now enjoys walking and often uses walking as a form of entertainment. Now, he walks a lot, but his walk is unstable. Jack will look for circular routes outdoors or in buildings and, with help, can walk a mile or more. Though he can walk quickly and even run, he is prone to stumbling and falls. All walks require close supervision because of the fall risk and because he is unaware of any risk of danger such as traffic.

Jack’s favorite activity is watching choice music videos, but he cannot independently change videos or adjust the volume on a video player. He will inadvertently knock over a portable player, often damaging it. He can learn to stop or restart a video if the same player is used for months at a time.

Jack requires constant supervision. He does not understand dangers. He does not know to avoid broken glass or open flames. He is unaware of the dangers of cars or even the concept of getting lost.

Jack needs direct, physical aid with all daily activities. Jack cannot prepare food or drink, and he cannot chew difficult foods. Foods must be cut up for him. He can participate in feeding, but cannot use utensils independently. He requires hand-over-hand support to use a spoon or fork. He can drink from a cup, but often spills much of the fluid. He cannot brush his own teeth, shave or dress himself, though he will participate by putting his arms through each shirt sleeve and by lifting one leg for at a time to put on pants. To wash his hands, Jack requires direct hand-over-hand support and he cannot bathe himself.

Toileting is very inconsistent and difficult and cleanup can be dangerous. Jack requires a great deal of assistance with toileting. Because he does not initiate toileting on his own, every two hours he must be encouraged to go into the bathroom. Behavior modification professionals have helped achieve some limited success with Jack’s toileting. It often requires 10 to 20 minutes to usher Jack into the bathroom, but then he is frequently unsuccessful in voiding. When he does pee or have a BM, care must be taken to keep his hands from his penis and prevent him from standing while he is peeing.

Often, efforts at toileting do not prevent a pee or BM in his pull-up. Because of Jack’s highly variable bowel activity, he may have a very large and/or loose BM that soils himself and his clothes. Cleanup can be very complicated because if Jack chooses to resist, it can require two strong people to take him to the bathroom. If he isn’t cleaned or during cleanup, he could spread urine or feces into his own mouth or eyes. Also, despite a history of falling in the bathroom, Jack is not aware of, or ignores the dangers of wrestling in the bathroom.

Sleep is another difficult problem for those with \_\_\_\_ Syndrome. Jack suffers from delayed sleep and remaining asleep. Some nights he has virtually no sleep at all. Although he becomes tired in the evening and takes medications nightly to help with sleep, he is often not able to settle down until 3 or 4 AM. He usually awakens once or twice during the night. If someone responds quickly enough, Jack can be ushered back into bed and will fall back to sleep. If no one responds quickly to settle him back into bed, there is a renewed risk that he will not be able to fall back to sleep.

**Eligibility Letter of Support from Parent: Beth**

Beth was a perfectly healthy baby. When she was 2 months old, I found her in bed not breathing. We rushed her to Georgetown University Hospital. It was an interrupted SIDS (sudden infant death syndrome). Beth was in a coma and when she came out of the coma, the neurologist said that Beth would never walk, talk, see, or be independent due to severe, global brain damage.

**Beth’s Daily Support Needs**

**Morning**

Beth wakes up between 5am and 7am. Beth is nonverbal and cannot talk. So she calls out “ah” until I respond. I roll Beth over in bed so that I can remove her diaper. She cannot turn herself over. I pull Beth to a sitting position by the side of the bed and hold on to her because she cannot sit independently. Then I lift her out of bed and onto the nearby portable commode. She is securely strapped in for about 10 minutes while I collect warm water in a basin, feminine wash, a towel, washcloth, and put a waterproof pad on her bed. Beth usually urinates in the toilet. I wipe her off and lift her back onto the bed. I wash between her legs and pat her dry with a towel, making sure she has no rash or irritation. This should be done 2 to 3 times a day to prevent a urinary infection. I use the same rolling technique to put on her new diaper, clean pants and socks.

I pull Beth into a sitting position by the side of the bed again and lift her into the wheelchair. The wheelchair can be rotated backward so that we can pull Beth from underneath her arms and assure that her behind is all the way into the seat. The back of the seat has been specially constructed to counter act Beth’s scoliosis. The wheelchair is then rotated back to a normal upright position and her seat belt attached. We put Beth’s clean shirt and soft stretchy sweater on while she sits in the wheelchair. Her arms are usually bent at the elbow and we struggle to get Beth to “relax” her arms. My last task is to empty the bucket from the commode, clean it and the toilet seat with Lysol.

Beth is ready to be pushed into the kitchen for breakfast. For her reflux disease, I give Beth a Nexium capsule wrapped in cheese so she will swallow it. We make her breakfast. Beth can hold a modified fork or spoon but she needs my hand under her elbow to get the food to her mouth. All food is cut into small morsels or mashed to prevent choking or aspirating. She needs a balanced diet to prevent weight gain because Beth cannot walk, run, or be physically active. Beth drinks from a cup. She can put her thumb through the handle but she needs me to hold the cup for her and she spills a lot of the liquid. We add fibers to her food to aide her digestion. Breakfast takes about 45 minutes to an hour because we encourage Beth to use her hand and arm as much as possible. Beth’s muscles are very tight, her wrist is crooked, and it is hard for her to relax her arm to scoop up the food. I give her lots of praise.

Following breakfast, I wash her face and hands, brush her teeth, and brush her hair. Beth wears adaptive orthotics on her feet called AFOs. We exercise her feet by stretching her ham strings and tendons for 5 minutes each before putting on her orthotics. Once the orthotics are on her feet, we can put on her special shoes. Beth hates these exercises, partly because they are uncomfortable and her muscles are very tight. She cries and complains during the process and tries to kick off the orthotics.

We put on Beth’s coat and hat and walk outside until the van arrives because Beth prefers to be outside. The wheelchair accessible van takes Beth to school.

**Afternoon**

When the van returns Beth home around 4pm, we take her to the kitchen. She is usually thirsty and has a drink and a small snack. We often take Beth for a long ride in her wheelchair to the park. When she returns home, we remove her AFOs to give her feet some freedom. I file her toe nails and put on medication for the infection. We also file her fingernails every week. I wash her hair at the kitchen sink by reclining her wheelchair all the way back. I wrap her hair in a heavy towel and then help Beth to hold the hair dryer. With my hand over hers, we manage to dry her hair. She objects less to this activity if she is participating.

Beth has constipation. Each afternoon I lift her from the wheelchair to her bed, take off her diaper, and administer a Fleet enema. I lift Beth onto her commode and put on her safety belt so she doesn’t fall off. After 10 minutes I check to see if she has done a BM. If not, we wait longer. If this fails, Beth ends up doing her BM later in her diaper. I lift Beth off the toilet and back onto the bed. I empty the commode immediately and sterilize it. I wash Beth between her legs with soap and water. Sometimes I give her a sponge bath because I can’t give her a bath in the tub without additional help from other people. I check her for any sores or skin breakdowns. I roll her back and forth to put on her diaper and pajama pants. I lift her into the wheelchair and put on her pajama top.

For dinner, it takes about an hour to assist Beth to eat and feed herself. Beth enjoys eating and she will make a soft “ah” sound if you ask her, “more to eat?” It is essential to engage her during the meal. Beth knows the words for various foods, like “cookie,” “juice,” “ham,” “hot dog,” etc. On the other hand, she turns her head away if she doesn’t want to eat more and she will drop the spoon or fork as well. At the end of dinner, we wash her hands and face and brush her teeth. We put her hand on the electric toothbrush so she can participate and accept the intrusion into her mouth.

After dinner, Beth can push the keys to make music on a small, adaptive keyboard or listen to books on tape. We need to keep talking to her and reassuring her that she is not alone or she will makes loud, angry sounds. Beth enjoys alternate seating, such as a soft couch. She can be transferred out of her wheelchair and seated on the sofa with us but it takes two people to do this. Beth is cortically blind and her vision is limited to about 3 feet. We are not sure exactly what she does see or if her brain processes the image. However, she does recognize me, her dad and her brother.

At 7:30pm we give her 6 mg of Melatonin, an herbal remedy recommended by her doctor to help her sleep. She is wheeled into her room between 8 and 8:30pm. I lift her out of the wheelchair and into bed. We offer her a drink before saying goodnight. We have a white noise machine that has the sound of “waves.” We put this on so she won’t hear us going up and down the hallway to our room. There is nothing wrong with Beth’s hearing! We leave a night light on as well.

Beth will call out 2 or 3 times before 11pm. We go in and sit her up on the side of the bed and give her a drink. As I said, she takes Nexium and it makes her mouth dry. She will drink ½ cup of water several times. We turn her over. Often she will burp or pass gas so her calling can be the result of indigestion or gas pains. Periodically, she gets very upset and cries in the middle of the night. But she cannot tell us what is wrong. It could be from stomach pains. We see a lot more complaining and distressed behavior before her monthly period. During those times of the month, we give Beth Midol or Motrin, again wrapped in cheese for easy swallowing.

Because Beth has no other way to tell us that something is wrong except by crying, we don’t ignore her when she cries in the night. Her limited communication devices do not cover the range of discomforts and needs Beth might have at night. We check on her to see if she has thrown up, has a temperature, is thirsty, due for her period, etc. There is always the possibility of having a urinary infection as well because Beth has a history of such infections.

If Beth sleeps for 6 hours straight, she often wakes up at 5am and complains until I get her up.

On weekends and holidays, her dad and I take turns looking after Beth. One of us has to be with her at all times. Her dad takes her outside in her wheelchair with him as he works in the yard. Beth stays with me in the kitchen otherwise. One of us will take her in our wheelchair accessible van when running errands so the other person can be free to complete projects, fix cars, grocery shop, etc. Unfortunately, I can no longer pull Beth’s wheelchair up the ramp into our van. I wait for someone to walk by in the parking lot and ask for help. Whatever our schedules, we both have to work together three times a day to change Beth’s diaper.

**Priority Category**

Beth cannot expect total assistance for all her needs from us, her parents and caregivers because of our injuries sustained over the years. Beth weights 125 pounds and has the body of a young woman. However, she cannot stand up, use her legs or arms to transfer herself or turn herself over in bed. Her dystonia and spasticity (tight muscles and twisted wrists and feet) make it difficult for Beth to function and for us to care for her stiff body. Beth requires complete lifting and transferring assistance to move her from the bed, wheelchair, toilet, bathtub, or changing table at home or at her weekday program. On holidays and weekends, this total assistance is required at least 3 times a day at home. If Beth is left to sit in her wheelchair for long time periods and her diapers are not changed, it will result in urinary infections and skin breakdowns. Also, she has had spinal fusion surgery to correct most of her scoliosis so there is a rod attached to her spine. We are sure her back starts to hurt after a few hours of sitting. She should be taken out of the wheelchair and laid on a bed to stretch out her back muscles.

It requires strength to roll Beth from side to side in her bed when we are changing her diaper or putting on clothes. The lifts and transfer necessitate two capable caregivers working together to execute a safe transfer. We are not able to continue to provide a safe and healthy environment for Beth to live in without danger of injuries from falls due to Beth’s weight, immobility, and our progressive physical problems as we get closer to our 70s.

I am 64, work full time, and am the primary caregiver for both Beth and my elderly parents who have had ongoing serious medical problems. I cannot lift Beth because of damage to my shoulders and left knee from lifting and transferring Beth, especially in the last few years. Beth has slipped out of my grasp twice: April 5, 20\_\_, and February 22, 20\_\_. Both times, Beth hit her forehead and was rushed to \_\_\_\_ Hospital in \_\_\_\_, MD. My other medical conditions include diabetes. I have had several near fainting episodes due to sudden low blood sugar. On December 21, 20\_\_, I had such a spell and ended up in the emergency room. I also began taking blood pressure medicine in March 20\_\_. The stress of working, taking care of Beth, and caring for my parents contributed to my increased blood pressure.

Beth’s dad is 67 and has sustained hernias from lifting, transferring, and trying to provide assisted walking for his daughter. Following surgery to repair the hernias in 20\_\_, he was advised by his doctor to limit his physical activities with his daughter or he could re-injure the groin area. Her dad has also torn his right arm bicep tendon rescuing Beth in a near accident situation in December 20\_\_. He is waiting to hear the results of a recent MRI to see if any repair can occur but his doctor is not hopeful. In addition, he now has a “tennis” elbow: this is an inflammation on the upper left arm near his elbow resulting from repeated lifting of Beth. There may be a partial tear of the tendon fibers. He is using a splint for 3 weeks to keep his forearm and elbow still. He needs to limit any strain on that arm. Unfortunately, he has been doing the major share of lifting Beth for the past 9 months as I have been unable to do the lifting required for Beth’s care.

When Beth’s dad travels for his job at \_\_\_\_, I am alone in the house with Beth. I worry about an emergency or a fire and how I would get Beth out of bed, into the wheelchair, and out of the house safely. With my diabetes, I have had several near fainting episodes due to sudden low blood sugar. What would happen to Beth if I collapse and her dad isn’t home? These are serious concerns for us.

**Priority Category**

I am Jack’s primary caretaker and I cannot keep Jack safe either in our home or when he and I go out together. My husband works full time and frequently works overtime in his job as a\_\_\_\_. Jack needs direct hands-on assistance with all activities of daily living. He needs supervision and physical assistance with all recreational activities.

Jack is shorter than I am, but weighs almost as much as I do. I am \_\_ years old and \_\_ pounds. I cannot protect him when he is uncooperative. He sometimes does not understand my requests, and sometimes he does not understand the danger of noncompliance. Not only does he put himself at risk, but it also puts me at risk for serious injury or death. The situation is very serious and very urgent.

Both Jack and I have fallen in the bathroom while Jack was resisting toileting or cleanup. Jack is very strong and quite single-minded when he resists me. Recently, on August \_\_, \_\_ and \_\_ and on September \_\_, \_\_ and \_\_, I was in the bathroom with Jack, cleaning up feces on him, me and the floor, when Jack has either become confused with my requests or convinced he wants to do something else. His hands went everywhere, including into my face. On August \_\_ and September \_\_, he and I both slipped on the unsure footing of feces on the floor. He pushed away from me as I tried to keep both of us from falling.

The consequences to Jack of previous falls are unclear. He is unable to report symptoms related to head injury. Jack’s naturally poor neurological state (intellectual dysfunction, history of seizures) predisposes him to more serious long term consequences, even to small injuries that might not be serious for more healthy individuals. His likelihood of recovering from a serious head injury is significantly less than the general population.

On my own, handling Jack is a dangerous daily task and I worry about injuring myself during a fall. Jack’s body weight is nearly equal to my own and he acts without regard to the dangers of falling. I make a great effort to protect Jack in the bathroom. As a result, when he pushes or pulls me while I am trying to clean him up, my balance is often disturbed more than his and my arms are not positioned to protect myself in case of a fall.

Though Jack is usually cooperative when I take him to doctor appointments, community and family events, he sometimes decides otherwise. He will suddenly either struggle to move away from me or lie down on the ground. He will run into traffic if not stopped. He has lain down in parking lots and in the crosswalk of a street. On August \_\_, I stood over Jack in the middle of a street waving off traffic. I am too small to lift him to safety, so I have to wait for him to cooperate and pray we are not struck by a car. On July\_\_, he quickly changed directions and headed for a cliff’s edge. I avoided his certain death only by tackling him to the ground. Taking Jack out puts both of us at risk of injury or death.

Jack needs more support than his father and I can provide for him. He needs constant close supervision to protect him and sufficient support to handle potentially dangerous moments, like during outings, toileting and unplanned cleanup.