



August 28, 2015

Dear Subcommittee Members,

The number of individuals living with intellectual (ID) and developmental (DD) disabilities is growing due to their increased longevity. Providers, families and caregivers are attempting to manage multiple, complex, chronic conditions within a system that is financially unprepared to address the needs of the aging population of persons with intellectual or developmental delays. There is a challenge to provide more evidence-based practice standards to enhance the health status, longevity, functional capability and quality of life for this population.

- **People with ID/DD are living longer and experiencing issues similar to the general population relative to aging and health conditions. The nursing care should broaden its focus from making gains in employment and independence status to that of maintaining function and dealing with eventual loss and decline.**

The current reimbursement rates fall short of providing adequate, individualized nursing care for consumers to remain living indefinitely in their own homes. For individuals receiving Supported Living Services (category 2 with 60 hours annually for nursing) the new rate of reimbursement for all combined services provided (including nursing) is bundled into \$225.38 a day; at most this pays for up to 10 minutes of face to face daily nursing (excluding travel time, documentation, on call and related phone conversations, and assuming that the consumer's budget has services covering 365 days of the year). In comparison, Genworth's Life and Annuity Insurance Company reports the cost of an institutional nursing home room, supervision, and medication administration in Las Cruces, New Mexico is \$271. For hospital inpatient status, the daily cost rises to \$2,175 for non-profit hospitals or \$1,895 at for-profit hospitals according to the Becker Hospital Review.

Tresco is requesting that this information be considered for additional funding for the delivery of nursing care for Supported Living Services.

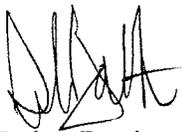
- Rationale: The current national average life expectancy of people with ID/DD is about 60 years. In 1960, the life expectancy for a person with Down syndrome was 47 years old, and in 1960, the expectancy was 10 years (CDC).
 - E.g. the average age of an adult consumer at Tresco, Inc. is 48 years with ages progressing to 72 years.
- Rationale: Comorbidities associated with ID/DD and the aging process are often compounded by communication difficulties and dependence on others for monitoring and responding to needs, which could delay treatment or recognition of subtle changes in health status and increase the cost of care. Some ID/DD syndromes are associated with earlier onset than in the general population or anticipated manifestations of symptoms related to aging.
 - Visual impairment is commonly found in 66.7% of older persons with ID/DD and Down syndrome.
 - Hearing loss is 40-100 times more common than in the general population.
 - Poor oral health, obesity, thyroid disease, sleep apnea, cardiovascular disease, intestinal issues, and dementia are prevalent within the ID/DD population.
 - Osteoporosis may develop more rapidly due to restricted mobility or in association with anticonvulsant medications which results in higher numbers of injuries related to falls. This condition is also associated with loss of peak bone mass after menopause in females which increases their fracture risks.
 - People with ID/DD have a higher risk of schizophrenia and depression (15% of cases), behavioral abnormalities (40% of cases), aggression, self-injury, and epilepsy.
 - E.g. a 2012 *Neurosurg Focus* report found the yearly cost of epilepsy increased 137.9% to \$23,909 over a 15 year

period despite a 33% decrease in the average length of patient hospital stay.

- Down syndrome is frequently comorbid with Alzheimer disease and progression is seen at an earlier onset and a more rapid rate of decline.
- Rationale: Psychological and social life stages are complex and are an area needing more research and attention.
 - Ethical consideration of rights to refuse, patient (and Case Manager or Guardian) level of understanding, and informed consent, need evaluated and time allotted to achieve shared healthcare goals and should be considered in the nursing reimbursement rate.
 - Health promotion and disease prevention strategies for the aging ID/DD population need to be tailored to the individual, address primary and secondary disease prevention rather than chronological age, and decrease or prevent recurring hospitalizations.
 - ID/DD consumers who wish to die at home should be offered home palliative care within the DD Waiver system, delivered by their current care givers and nurses, and needs to be considered in the nursing reimbursement rate.

We must all take steps to change the way nursing care is provided for our consumers; to reward care that is better coordinated and meets the needs of each individual. In particular, Tresco, Inc. is requesting that the Subcommittee endorses that additional funding for nursing care is needed.

Respectfully,



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Tresco, Inc.