Nursing home placement

Adult Down Syndrome Clinic on Tuesday, August 31, 2010

A question was sent regarding a person living in a nursing home.

Placement of individuals with Down syndrome in nursing homes has been a challenging issue for a number of years. In Illinois, in the past many individuals with intellectual disabilities were sent to live in nursing homes. In 1987 a class action lawsuit was filed on behalf of these individuals who didn't need nursing home care. They were inappropriately placed. They didn't have medical needs that required nursing home care. The outcome was the opportunity to live in more suitable residential facilities. More information regarding the lawsuit and outcome can be found at the following web page:

http://newsletter.csfil.org/index.jsp?CAMPAIGN_ID=443&content_id=805%EF%BB%BF

The focus for years has been getting people out of nursing homes who are inappropriately placed. The question that was asked, however, and one we frequently address is about getting a person with Down syndrome a place in a nursing home.

The key is that the diagnosis of Down syndrome is never (in our experience) the diagnosis or the reason for providing services for a person with Down syndrome in a nursing home.

However, there may be other diagnoses that require a level of care not available in the family home or the residential facility.

Sometimes a short stay is needed. This may be for:

- physical or occupational therapy after a surgery or hospitalization
- completing a course of intravenous antibiotics
- care of a wound
Sometimes long-term care may require nursing home care. In our experience some examples have included individuals who:

- have developed Alzheimer disease
- have developed complications from an illness
- require care for medical devices

One could argue that some of that care could or should be given in one's own home—whether it be the family home or a residential facility. This is often a valid argument but one that has been discussed for much longer for people without intellectual disabilities for whom sometimes the only available solution is nursing home care. In-home care may be preferred by some and may be cheaper in some situations but the level of care needed is often not available except in a nursing home at this time.

For group homes (residential facilities), sometimes it comes down to a philosophical approach. Some agencies have decided to care for the individuals with intellectual disabilities throughout their lives. They adjust their services based on the individual's needs and the changing health issues. Others have clearly defined their mission as caring for and habilitation of people with intellectual disabilities and don't see themselves as having the resources or expertise to care for these other issues that arise (for example advanced Alzheimer Disease). I don't think there is necessarily a right or wrong approach but it needs to be clearly defined and discussed.

In whatever setting a person lives, we recommend:

- make a good and realistic assessment of the individual's needs and the capabilities of the home where he lives to provide for them (including state regulations for care- for example, residential facilities are usually not licensed to provide intravenous medications)
- explore in-home assistance options
- discuss the philosophical approach with the agency if the person lives in a residential facility
- explore nursing home or other options

The question posed was regarding how one qualifies for the nursing home. The key for us has been using the diagnosis for which the nursing home care is needed and not using "Down syndrome" as the diagnosis. As previously noted, we have not seen an individual for whom the diagnosis of Down syndrome made them an appropriate person to go to a nursing home. On the other hand, we have seen many individuals who have a diagnosis of Alzheimer disease, for example, who also happen to have Down syndrome. In some cases, having the diagnosis of Alzheimer disease made them appropriate for placement in
a nursing home. The emphasis has to be on the diagnosis (and thus the need) for nursing home placement and away from Down syndrome.

In our book coming out next month, there is a section entitled "The Right Environment" in the chapter on Alzheimer Disease. I recommend taking a look at it: