

SEATING FOR INDIVIDUALS AGING WITH INTELLECTUAL DISABILITIES

Let's face it – aging is not something we look forward to. On the other hand, it remains a better option than the alternative. Aging provides challenges to all of us. Imagine what the process is like if you also have an intellectual/developmental disability. As the life expectancies of such individuals continue to rise, more and more will experience difficulties with mobility. By definition, an intellectual disability is characterized by significant limitations in both intellectual functioning and in adaptive behavior, including many everyday social and practical skills. The onset has to be before the age of 18. The terms intellectual disability and developmental disability are often used interchangeably. Developmental disabilities are characterized by difficulties in certain areas of life, especially in language, mobility, learning, self-help and independent living. For the sake of discussion, we are going to focus on those individuals with intellectual/developmental disabilities resulting physical impairments, but not including neurological conditions such as cerebral palsy.

When the process of aging begins is under much debate. As we age, the threshold for “being old” increases. The concept of “old” is often based on perspective. For a 5 year old, “old” might be 10 years old. For a 60 year old, “old” might be 80 years old. So what is aging? By definition, it is the general decline in physical and sometimes mental functioning. All body systems are affected, some more than others. Most importantly, it should be noted this is a normal process, whether we like it or not. Generally speaking, aging starts at the peak of growth and development, usually by one's late teens to early 20s.

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Aging and its impact are based on the interaction of three factors. Some of these we have control over and some we do not. They include lifelong choices, environment and genetics. Obviously we have control over lifelong choices, including diet, physical and mental exercise and habits. We have some control over environmental factors – where we live, what social choices we make as well as cultural influences. The third factor, genetics, is bred within us and gives us no opportunity to change.

However, the genetic link can help guide us when making other choices. Individuals with intellectual disabilities have life choices imposed upon them. Due to cognitive limitations, decisions are often made by others “in their best interest.” These decisions may not be best for the individual, but may be more convenient for the family and/or caregiver.

When aging with an intellectual disability, the interaction of these three areas may result in greater issues, including:

- Increased risk factors with earlier onset of symptoms;
- Increased risk for inappropriate medical treatment;
- Increased risk for a more restrictive environment;
- Increased tendency for challenging behavior, often due to communication difficulties;
- Increased cost for treatment and interventions; and
- Increased caregiver frustration due to lack of knowledge and communication.

The last issue can be pivotal in decisions that are made for the individual.

Diagnostic overshadowing occurs in individuals with intellectual disabilities. Medical professionals less familiar with these individuals tend to “blame” changes on the obvious disability. Infrequently are they referred to specialists or the symptoms challenged to find the true cause. This leads to either misdiagnosis or the lack of diagnosis of other disease processes, decreased vitality/quality of life and increased behavioral changes.

CHARACTERISTICS OF AGING

So what are some of the common characteristics of aging? All body systems are impacted. Individuals with intellectual/developmental disabilities lack the ability to compensate for the early changes; this can make the changes appear more significant. Senses tend to dull. Hearing impairments develop with high tones affected initially. Vision changes occur leading to decreased acuity, as well as the development of age related conditions (i.e. cataracts, macular degeneration). Vision changes can be seen in terms of mobility limitations; the individual may be hesitant to move due to a lack of visual cues. Olfactory and gustatory changes occur; food doesn't smell or taste as strongly as it once did. This can lead to decreased appetite, which in turn leads to decreased energy. Combined with cognitive limitations, these age-related changes may present as disinterest, boredom or stubbornness from a caregiver's perspective. Interest in mobility may be decreased, however, it may simply be a symptom of aging issues.

Physically, body changes occur. The proportion of fat to muscle shifts with loss of muscle mass, leading to muscle atrophy and loss of strength. Fatty deposits under the skin tend to shrink while fat accumulates around the stomach. This, in combination with skin changes (loss of elasticity and thinning), increases the potential for pressure ulcer development and other skin issues. Most importantly from a seating perspective, immobility increases as strength and endurance decrease. As mobility decreases, weight may increase and lead to further issues.

Aging impacts the function of most organ systems. The ability to breathe relies on postural muscles for efficient function. As muscles lose mass and coordination, respiratory difficulties can occur as a result. Oral motor skills can also be affected by aging. The digestive process may "slow down" due to a decrease in stomach acid production. This acid, along with chewing, starts the breakdown of food into nutrients. If the food is not well-digested, the intestinal system becomes less efficient, being unable to further breakdown substances for use and displaying decreased motility of the substance. Consequently, decreased appetite, stomach discomfort and constipation are possible.

Cognitive changes are also observed as individuals with intellectual/developmental disabilities age. Processing times for simple requests might slow and memory issues become more frequent. In addition, the early onset of Alzheimer's disease is seen in individuals with Down syndrome. This is characterized by early onset with rapid decline; the first sign is difficulty with daily function. Individuals may lose the ability to use information that was once known or learned. Delayed responses and memory issues can be interpreted as disinterest, non-compliance and increased "stubbornness."

Another area that impacts those with intellectual/developmental disabilities is medications. Polypharmacy occurs as these individuals often have numerous medications prescribed. If supervision is limited, proper use of medication may or may not be present. In addition, multiple side effects and drug interactions can occur.

The cumulative interaction of these aging issues, combined with cognitive limitations, can lead to significant mobility issues. The impact on mobility tends to be slow in onset but becomes a never-ending circle: overall speed of ambulation and movement decreases; balance reactions become delayed leading to the potential for increased falls; and hesitancy to move from one location to another is observed.

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PICTURE 1

Use of basic transport wheelchairs can be a simple solution when mobility changes cause difficulties during long distances.



PICTURE 2

Use of a folding base with a basic seat cushion offers a lightweight, transportable option that can help bridge the gap between a basic transport wheelchair and a tilt in space system. changes cause difficulties during long distances.



PICTURE 3

Use of a lighter weight wheelchair with tilt in space can offer greater adjustability in terms of size, seat to back angle, and overall height. This meets changing mobility needs.

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This all cycles back to further decrease participation in motor tasks. As this cycle starts, alternatives need to be discussed.

PROVIDING SOLUTIONS

Use of mobility aides (i.e. canes, crutches, walkers) has limited success with individuals aging with intellectual/developmental disabilities. If ambulation with a walker begins early in an individual's life, use generally can continue throughout the aging process. Introducing a mobility aid as ambulation changes occur is usually not successful. As previously noted, further cognitive and memory changes occur that limit the ability to learn or remember a new task. Instead, the mobility team needs to complete a full evaluation to determine how and when mobility assistance is needed. What part of mobility is difficult? What environments need to be addressed? Ambulation may be adequate within the residence, but not for outside. Is the issue related to strength and endurance rather than coordination? Is there a safety issue because of recent falls? Since the aging process is progressive, a mobility evaluation with a therapist and RTS/ATP is the best place to start.

WHAT PART OF MOBILITY IS DIFFICULT? WHAT ENVIRONMENTS NEED TO BE ADDRESSED? AMBULATION MAY BE ADEQUATE WITHIN THE RESIDENCE, BUT NOT FOR OUTSIDE.

During the evaluation process, the team needs to address what the individual's mobility history has been, including the rate of change and prognosis. Funding sources and requirements must be

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discussed, but the focus needs to remain on the individual's needs. Goal generation begins with the referral process and continues throughout the evaluation. Solutions need to address the immediate goal while being mindful of the potential for change.

If ambulation is difficult outside of the home, a basic transport wheelchair is a safe solution (see picture 1). Third party payment is not often available; however, transport chairs can be purchased through local drug or discount stores and are relatively inexpensive. Features need to be matched to the individual, including seat dimensions, rear wheel size (for self-propelling versus dependent), upholstery type, foldability, removable footrest hangers, chair weight and occupant weight limitations. For additional comfort, low-cost foam cushions can be purchased to place on the sling seat. If additional postural support is needed, a solid insert can be added under the seat cushion, but inside the cover, to help provide a more stable base of support, eliminating the hammocking effect of the sling seat.

Once an individual's mobility needs include "in the home use" (which is required for Medicare funding), there are more factors to consider. Options will be dictated by funding sources; however, it is important that families be informed of all options. This allows decisions to be based on needs, not just funding. A full mobility evaluation is imperative to help make those decisions. Key items to look at include means of mobility within the residence, cognitive and physical abilities to perform pressure reliefs and potential means to actively participate in mobility. Options include more traditional bases that allow for self-propelling or the use of a tilt-in-space (see pictures 2 and 3). Traditional bases offer foldability and greater ease to transport without a customized vehicle. However, tilt-in-space wheelchairs offer greater adjustability for anticipated changes in status, as well as an option for dependent pressure relief. If self-propelling is an option, the use of a lighter tilt in space base with rear axle adjustability needs to be explored. From experience, self-propelling a manual wheelchair is not usually a goal at this point in the individual's life, however, discussion needs to occur so all team members are on the same page.

In addition to mobility needs, skeletal and postural issues have to be addressed. Although specific neurological diagnoses are often not present, postural asymmetries need to be identified and possible solutions discussed. If funding is pursued, solutions may be limited by diagnosis. Again, it is the team's responsibility to discuss all possible options with the individual and caregivers to allow them make an informed choice. Without specific diagnoses, funded options include general use seating. With the addition of specific diagnoses, such as Alzheimer's disease, options expand to include positioning components. The use of a mobility base with adjustability in seat depth and seat to back angle can make up for lack of adjustability in hardware if general use seating is recommended.

A typical system that is recommended for an individual aging with an intellectual disability who is no longer ambulatory within his residence needs to offer the following:

- A means for dependent pressure relief;
- Seat to back angle adjustability;
- Ability to accommodate necessary seating and postural support for proper postural alignment; and
- Adjustability for future change.

Without these options, long-term use of the system will not be possible. When funding is available, make sure to maximize the opportunity by recommending as much adjustability as possible. Always think long term. Don't lock yourself into a system that meets only the immediate needs.

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CONCLUSION

Due to recent advancements in modern medicine and improved care, issues related to aging are now impacting individuals with intellectual/developmental disabilities. Life expectancies are increasing, as are the expectations of participation in life tasks. We are seeing complications and aging related changes in this group that further limits their abilities. Mobility is often one of the areas that sees dramatic changes, not necessarily due to mobility issues, but maybe due to other aging changes. Mobility options are available, but require a comprehensive seating and mobility evaluation. Recommendations need to be made based on client presentation with regard for the need for change as well as funding limitations. Once a team determines needs, recommendations can be made for the individual and caregivers.

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