



**GOOD COMPANY:** Those with IDD may have difficulty understanding their own need for greater support and care. In many cases, problems are underestimated as supporters fail to recognize symptoms of age-related health issues.

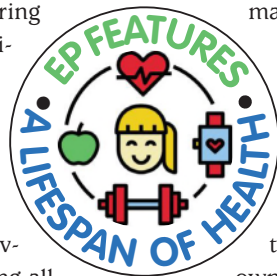
# AGE-RELATED MEDICAL CONDITIONS GOING UNRECOGNIZED, UNTREATED IN PEOPLE WITH IDD

SUBMITTED BY INTELLECTABILITY

*The population of the United States is getting older quickly. By 2050, it's projected that approximately 90 million adults will be over age 65.<sup>1</sup> By 2030, it's anticipated that one in five Americans will be 65 years old or older.<sup>1</sup> These estimates include a large number of people with intellectual and developmental disabilities (IDD).*

People with IDD are just as likely to suffer from the same age-related ailments as any other person. Dementia, Alzheimer's disease, arthritis, vision and hearing loss, and many other chronic health conditions affect large numbers of people with IDD, but signs of those problems often go unnoticed by supporters.

Dr. Craig Escudé, President of the IDD education and training firm IntellectAbility, says, "Since people with intellectual and developmental disabilities are living longer, we have to shift to ensure we're addressing all the factors that affect individuals as they get older. Supporters need to learn to recognize how chronic conditions like dementia might appear differently in a person with IDD."



According to the Association on Aging with Developmental Disabilities, the average lifespan of a person with IDD is approximately 70 years old – fairly close to the average American's projected lifespan of 77 years.<sup>2</sup> But little is known about how these individuals' lives change over time.

As with anyone else, it's important for a person with IDD to continue living on their own terms. That includes maintaining health and maximizing function, as well as reducing the impact of chronic diseases.<sup>3</sup> But those with IDD may have difficulty understanding their own need for greater support and care, while also struggling to communicate with others about that need. In many cases, problems are underestimated as supporters fail to recognize symptoms of age-related health issues.<sup>4</sup>

Dr. Seth Keller, Past President of the American Academy of Developmental Medicine & Dentistry, co-President of the National Task Group on Intellectual Disabilities and Dementia Practices, and Chair Adult IDD Section of the American Academy of Neurology, says, “You must know the individual’s activities and abilities and see if there are any changes. Supporters must collect detailed information on how, when, and under what circumstances the changes are occurring. But don’t jump to conclusions – it might be normal aging or changes in social environments and the person with IDD is just reacting to that. Or, it could be a social decline, not a physical one. Supporters must recognize these factors, and that’s where training comes into play.”

## RECOGNIZING SIGNS OF AGE-RELATED ILLNESS IN PEOPLE WITH IDD

Unfortunately, people with IDD often show signs of earlier medical, functional, and psychosocial changes compared to those without IDD.<sup>5</sup> With those changes comes a variety of symptoms which may be mistaken for behavioral changes in a person with IDD, especially if that person doesn’t use words to communicate. Signs of age-related illness might include:

- *Distancing themselves from others*
- *Increased fear*
- *Loss of interest in daily activities*

But people with IDD are also at higher risk for cognitive conditions like dementia or Alzheimer’s. Signs of these diseases might include:<sup>3</sup>

- *Aggressiveness*
- *Hoarding*
- *Late-onset seizures*
- *Personality changes*
- *Sleep disturbances*
- *Forgetfulness*
- *Incontinence*
- *Loss of skills*
- *Wandering*
- *Verbal outbursts*

It can be extremely difficult to recognize these problems as symptoms of a disease, especially if a supporter hasn’t had sufficient training. Supporters include family members, paid staff such as direct support professionals, and can also include anyone in the medical field, such as doctors and nurses who help a person with IDD achieve a better quality of life. IntellectAbility’s Health Risk Screening Tool is designed to identify risk factors for conditions that worsen with aging. Also, training in person-centered support can help supporters become more aware of possible age-related symptoms

they may encounter in a person with IDD.

Mrs. Pamela Merkle, Executive Director of the Association on Aging with Developmental Disabilities, says, “Some disability behaviors can be mistaken for dementia. It is imperative that the clinician look at the medical factors first and rule out physical changes. As for the supporters, they have to trust their gut when it comes to changes. Aging happens to everyone; one has to look at the social as well as the physical before making any decisions.”

Aging in individuals with IDD is the same as in any other person. But certain factors can make it difficult to recognize the signs of aging, especially if the person with IDD doesn’t use words to communicate. For people with IDD who live independently, they may or may not grasp that they have a health issue. That’s why any supporter must be educated and trained to seek help whenever even the smallest issues are noticed. As it is now, many supporters misinterpret the symptoms a person with IDD shows, leading to potential misdiagnosis and unnecessary or improper treatment.

Dr. Keller says, “Parents and other supporters need to be aggressive in their healthcare and not wait until the individual with IDD is older. They should establish a medical foundation early so that the person can age well.”

To build an effective medical foundation, healthcare professionals must first recognize the value of a person’s life, regardless of their level of disability. They must strive to provide the same level of preventative care that’s offered to people without IDD. That includes bolstering a person’s sense of purpose. Part of the person-centered approach to care for people with IDD, Dr. Escudé notes, includes involving them in activities they deem valuable to their own lives. Supporters may include a person in social activities and events which help connect those individuals with the community. Ultimately, this boosts a person’s quality of life. Those activities should continue even if a primary supporter isn’t up to the task anymore.

Another factor to take into consideration is that just as the individual with IDD is aging, so too is the supporter. Often, the supporter – especially if it’s a parent – will predecease the individual with IDD. Mrs. Merkle says, “One thing that cannot happen after the loss of a supporter is to isolate the individ-

ual with IDD. That can lead to depression, regression, and even suicide.” Society can help prevent these issues by continuing to involve people with IDD in activities they enjoy with others in their community.

**A**ging is simply a fact of life, and everyone eventually experiences health issues, but it’s often worse for people with IDD. However, thorough training can help ensure that medical professionals and other supporters can recognize signs of age-related illness. That way, problems can be addressed sooner so the person isn’t impacted over the long run.

“We need to treat people with disabilities the same as everyone else and remove the stigma that’s associated with this group. We need to remove any and all fears of interacting with people with IDD to help create communities in which all members are valued for who they are,” Dr. Escudé says. •

## References

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### ABOUT INTELLECTABILITY



IntellectAbility provides tools and training to agencies, governmental entities and supporters of people with intellectual and developmental disabilities to foster early recognition and mitigation of health risks thereby improving health and wellness. IntellectAbility also provides numerous health-related and person-centered service trainings for supporters of people with IDD. Learn more at <https://replacingrisk.com>