



# What are Areas of Concern When Working with Aging Adults with Autism?

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### I just started a new position working with aging adults with autism in a residential setting. Can you highlight some areas that should be considered when working with this population?

Congratulations on your new role working with adults with autism as it is not only an incredibly rewarding experience, but often under resourced. There is a significant need for professionals like yourself who are willing to learn to be able to support a really amazing group of people. As you begin this career journey, it's helpful to be aware of some key areas that may impact your work. Aging adults with autism face unique challenges that can affect their physical health, changes in challenging behavior, and end of life care. Understanding these considerations will help you provide thoughtful, person-centered care. Another area of importance to consider is that you will be joining an established treatment team, in which there will likely already be care plans developed. Your role will be to maintain and improve upon those plans moving forward. Below we highlight some areas of consideration as you get started.



### Physical Limitations and Losing Skills

As you begin to navigate your new position, you will recognize that autistic adults may experience changes in their behavior, health, and how their autistic features present as they get older. Recent studies (e.g., Longo et al., 2024) indicate that autistic adults tend to have more physical and mental health issues than the general population, but it's important to remember that there's still a lot we don't know, and more research is needed to support the aging autistic adult population.

That said, what we do know is that many health problems seen in autistic individuals are also commonly seen in the population at large. This can include gastrointestinal issues, immune dysfunction, sleep disturbances, seizures, sensory sensitivities, and low bone density. On top of that, age-related physical changes such as altered gait and mobility, vision and hearing loss, swallowing difficulties, and changes in speech or language intelligibility may come into play. All of these things can affect daily life and should be considered to ensure that the care provided is appropriate, responsive, and supportive (Klein & Klinger, 2024).

In your new role working closely with autistic adults, you have the opportunity to make a meaningful impact on their health and well-being. Many individuals on the spectrum already have difficulty recognizing or interpreting internal bodily signals like pain, hunger, or fatigue. As a result, they might be unaware of gradual changes such as declining energy, loss of muscle mass, or diminished sensory perception. At the same time, they may expect to maintain the routines, tasks, and preferences that have always been part of their daily lives. This rigidity can make adapting to physical changes particularly challenging. Here's where your support really matters. The first way to support the individual is to familiarize yourself with your new agency's documentation processes. This can help to maintain consistency throughout the organization, which will be more beneficial to the individual by ensuring continuity of care. Another area of support is by implementing realistic achievable data collection. For new admissions to your agency this will help to capture solid baseline information so you can identify and address changes when they occur. For individuals who have a longer tenure at the agency than you, it is imperative to become familiar with the treatment plans that are already in effect, including the data collection procedures and how to continue to support the individual throughout their lifespan. Examples include typical sleep/wake cycles, hygiene routines, meal intake, physical capabilities, and impeding behaviors. Another way to help is to communicate with medical professionals to make sure they have the full picture. This can add to the decision making about adaptive tools and environmental changes that may be needed.

Additionally, you can help support the individual in understanding what is happening with their body in a way that makes sense to them. For example, we are currently supporting an individual whose mobility continues to change. Previously, this individual was very independent, able to walk on their own and engaged in activities such as showering, toileting and dressing without staff help. Throughout the last couple years, the team has seen a significant increase in falls and the need for more support. These individual values their independence and was resistant to utilizing adaptive equipment or accepting staff support. To be able to help the individual navigate the physical changes, the team worked to emphasize with the individual that these adjustments can prolong their independence, by limiting the falls and decrease the risk of injury. They are now utilizing a motorized wheelchair full time, and enjoy it (partly because it decorated with their favorite sports team), in instances where they need to be out of their wheelchair, they are alerting staff that they will be transitioning out of the wheelchair and may need support. While self-monitoring is the ideal goal to strive for, this may not be realistic for all individuals, and this may fall to a loved one or paid caregiver with processes in place for continuity.

It's also important to think about how aging affects thinking and memory. Changes in memory are a typical part of the aging process, even in the absence of developmental differences. Many autistic people already have challenges with executive functioning and memory, so aging can sometimes bring on a faster or more observable decline (Geurts & Vissers, 2011). It is important to remember that the first generation of children to be diagnosed with autism are now moving into older age and may be starting to experience dementia related symptoms. There is still a lot of information that needs to be researched in relation to this topic. Regardless, the likelihood for an individual to experience anxiety, depression, or other mental health challenges due to the changes that are occurring in their body and mind increases. While some individuals may not have an outwardly evident response, a person is impacted by their changing bodies and the likelihood of stress and worry surrounding them, and the team should be positioned to treat the mental health symptoms (Duffy, Gasiewski, & Redcay, 2024). By implementing the plan of care with empathy, knowledge, and adaptability, you can help aging autistic adults maintain their quality of life and feel supported through these changes.



### Reemergence of Challenging Behaviors

You may observe challenging behaviors that were thought to be out of their repertoire. Many individuals may have a history of engaging in behavior that has impeded their daily life. While challenging behaviors may have decreased or stabilized, a reemergence of these behaviors or the exhibition of new topographies of behavior may occur later in life. Assessment, environmental modification, and possibly more intensive behavior support services may be needed. On the other hand, some individuals you support may begin to engage in challenging behaviors that haven't been observed before. Changes in behavior that impede someone's ability to engage with their daily life may be observable indicators that there is a medical concern to be addressed, medication adjustments may be needed, or someone's cognitive status is changing. These are all signs that adjusted or new approaches are needed to support this person.

One example that comes to mind is an individual who began to bite themselves, and we had not seen this before. Upon record review, it was documented that this had occurred fifteen years prior, and a painful tooth abscess was found. The team booked a dental appointment right away and, sure enough, the individual did need dental work. Identifying the individual's history of how they have communicated pain in the past helped the team quickly address the cause. This is why accurate documentation across the lifespan is important.

As an additional example, an individual who typically was a happy person began engaging in challenging behaviors including ripping their own shirt, and taunting peers. These behaviors were not observed during their time with us, but as they aged, it began to impede his programming. The team had to put in antecedent procedures, by changing their day program location which had a more appropriate pace for them including more meaningful activities to be completed throughout the day. Additionally, clothing checks were completed, where all tags were removed from clothing, as well as checks to ensure that there was no fraying seams observed, and if observed, those articles of clothing were immediately replaced.

### End-of-Life Care and Planning

End of life care and planning is often a challenging topic for families to consider let alone discuss. You may find yourself in a position to help initiate or guide these conversations. People often feel that because their loved one is healthy, they don't need to think about it or plan for it now. In reality, it is beneficial to be able to plan for the end of life while the individual is healthy and death is not near. The end of someone's life is inherently confusing, stressful, and emotional for everyone involved. Initiating this difficult conversation early and establishing the plan allows for all care and resources to be allocated solely to the individual when they are near the end of their life. Conversely, delayed planning may delay or impede care to an individual when it is imminent and catch the family off guard.

A good way to begin these hard conversations is to approach it during your annual programming meeting. You can acknowledge how this is a lot to take in, and that it doesn't need to be decided in the moment. One uncomfortable but thorough conversation early and when they are healthy can make an extremely emotional and stressful time a little bit easier and allow you to focus elsewhere because a plan will already be in place. Conversations regarding the end of life can include the level of medical intervention (i.e. chemo, Do Not Resuscitate [DNR]/ Do Not Intubate [DNI] etc.), funeral planning, burial or cremation or another alternative, and the final resting place. Having these conversations early allows for the team to document them and know the plan. These decisions can change but they will at least allow for one topic to be covered prior to the increased stress and anxiety at the end of life.



### Bereavement

Bereavement, mourning and grief are a part of life, and as someone who is going to be working with the older adult autistic population you are going to help the individual with autism with navigating losing their families members and their friends. The people you support may have a particularly difficult time processing, understanding, and navigating scenarios where people they care about are experiencing a physical decline that impacts how they typically engaged with that person. When someone they care about passes away, there are many ways supporters and caregivers can show up for that person.

For example, if the person has a religious background, it can be useful to speak in terms that align with their religious beliefs. It is also helpful to stick with the facts, like highlighting that they are no longer in any pain and to also reflect on the good times that were had. Give the individual time and space to talk about the person they are grieving for, help them identify happy memories, connect with others who may be grieving the same loss, answer questions that they might have, and reassure them it is normal and okay to feel sad, to cry, and to have emotions that will feel difficult to manage at times.

### Conclusion

We hope the above discussion will help acclimate you to some of the unique experiences of working with older individuals with autism. We would like to reiterate that taking a position working with autistic adults will be an amazing experience! Your willingness to learn will be extremely beneficial in supporting this underserved population. While we have given you a lot of information, recognizing that each individual you may support will present with their own unique challenges. Maintaining your compassion while being armed with information will give you the confidence you need to enhance the care of your individuals and move our field forward.



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