Working With Older Adults With Developmental and Intellectual Disabilities in Long-Term Care

Brian D. Scaife, OTD, OTR/L
Assistant Professor of Occupational Therapy, West Virginia University, Morgantown, WV

Jennifer E. Lape, OTD, OTR/L
Assistant Professor of Occupational Therapy, Chatham University, Pittsburgh, PA

SueAnn Woods, MOT, OTR/L, CHT
Assistant Professor of Occupational Therapy, West Virginia University, Morgantown, WV

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ABSTRACT
As the average life expectancy increases in the general population, individuals with intellectual and developmental disabilities (IDD) are also experiencing an increase in life expectancy. This means that many are living with or have to manage symptoms related to their disability as well as symptoms associated with age-related declines and comorbidities. Because of these age-related changes and acute illnesses, they are often admitted to skilled nursing facilities for short-term rehabilitation and long-term care. Caregiving staff in these facilities often become frustrated with these clients’ behaviors and, at times, with what is perceived as refusal of therapy. This article explores various occupational therapy evaluation treatment methods and theories to assist occupational therapy practitioners in treating these individuals.

LEARNING OBJECTIVES
After reading this article, you should be able to:
1. Identify the historical policies that have affected care for adults with intellectual and developmental disabilities (IDD)
2. Describe challenges to addressing occupational therapy goals among adults IDD in the long-term-care setting
3. Identify triggers to challenging behaviors among adults with IDD in the long-term-care setting
4. Select strategies for addressing challenging behaviors among adults with IDD in the long-term-care setting

INTRODUCTION
Based on the latest National Vital Statistics Report, the average life expectancy of individuals in the United States is currently 78.6 years (Xu et al., 2018). Medical advances, improved sanitation practices, and increased education and focus on healthy living are all responsible for this increasing life span. Although individuals with intellectual and developmental disabilities (IDD) have historically experienced decreased life expectancy when compared with the general population, their life expectancy now ranges from mid 30s to late 80s, with the average life expectancy in the high 50s to low 70s (Bittles et al., 2002; Coppus, 2013; Okamoto, 2016).

This increased life expectancy in individuals with IDD means that many are living with or have to manage symptoms related to their disability as well as symptoms associated with age-related declines and comorbidities. This situation results in challenges for the individual as well as their family, caregivers, and medical professionals, who may not be adequately trained to handle the complexities and behavioral challenges that typically accompany these conditions.

Additionally, increasing numbers of individuals with IDD are being admitted to long-term-care facilities later in life, when these complexities and challenges can no longer be safely managed at home or in community-based settings. Therefore, the purpose of this article is to discuss specific behaviors and challenges encountered when treating clients with IDD in long-term-care settings and to offer a set of strategies that can be used by occupational therapy practitioners to navigate these behaviors and challenges to promote positive client outcomes.

DEFINING IDD
Variations in the definition of IDD exist depending on the source consulted, but the following explanation is adopted for the purposes of this article. IDD is a collective term used to describe the presence of intellectual disabilities alone or in combination with physical disabilities. Intellectual disabilities are typically diagnosed before the age of 18 years and are “characterized by significant limitations both in intellectual functioning (reasoning, learning, problem solving) and in adaptive behavior, which covers
a range of everyday social and practical skills” (American Association on Intellectual and Developmental Disabilities, 2018).

Adaptive behavior is the result of one’s adequate awareness of environmental contexts, and social cues and norms, to function effectively in all areas of life. In addition to intellectual deficits and the presence of maladaptive behaviors, individuals diagnosed with IDD may demonstrate limitations in physical functioning and emotional development, which can affect their ability to complete self-care tasks and mobility, and to interact socially in the same way as their typically developing peers.

DEINSTITUTIONALIZATION MOVEMENT

Historically, individuals with IDD, formerly referred to as mental retardation, were institutionalized. In the 1800s in the United States, this movement was led by Dorothea Dix, a rights activist who lobbied for funding and establishing what was referred to as institutions or insane asylums (Modak et al., 2016). It was believed that these facilities would offer more humane treatment for those with IDD or mental illness, though in reality, the reverse often occurred. These institutions, which became holding facilities for those with IDD and mental illness and were often described as “jail-like” provided custodial care, including medication, therapy, and even vocational training. In these institutions, patients had little autonomy, faced stigma related to illness or injury. Aspiration, dehydration, constipation, and seizure disorders, which are often not detected at onset, are more common in individuals with IDD than the general population and can lead to significant declines in medical status and overall function (Bailey, 2017). There is an increased prevalence of falls and fall-related injuries among this population, with many of the risk factors for falls inherent to these conditions. Risk factors include seizure disorders, taking more than four medications, using assistive devices for mobility, or other physical limitations (Hsieh et al., 2012).

Yet another reason for nursing home admissions is related to the fact that greater numbers of adults with IDD co-reside with their aging parents, when compared with typically developing adults (Seltzer et al., 2011). As they age and begin to deal with declining health, these parents may become unable to care for their adult children with IDD and seek placement elsewhere for them. Additionally, individuals with IDD can experience early-onset age-related health problems, including physical decline or dementia, which can affect their well-being and ability to be safely cared for in the home (Tse et al., 2018). Placement options could include community living or congregate care (group home) as well as a nursing home.

In alignment with the goals of deinstitutionalization, community or congregate living would be preferred; however, these arrangements require that all individuals are able to comply with disaster preparedness regulations to safely evacuate the home in the event of an emergency, and that the staffing ratio in the home allows for safely managing all individuals residing there. Nursing home placement may be the only option for individuals with IDD who also have significant physical or cognitive limitations that cannot be effectively addressed in community living situations.

LACK OF KNOWLEDGE

Despite the increase in nursing home admissions for adults with IDD, many health care practitioners report insufficient knowledge and confidence in managing the complex needs of this population (Pelleboer-Gunnink et al., 2017; Sajith et al., 2017). This lack of knowledge and confidence has led to erroneous expectations for individuals with IDD; rehabilitation professionals in one study felt that individuals with IDD were unlikely to benefit from interventions (Strauser et al., 2009), and nurses in another study perceived these individuals to be more challenging to work with and less cooperative (Lewis & Stenfert-Kroese, 2010).

Some practitioners have also expressed increased stress, fear, and anxiety associated with treating individuals with IDD (Pelleboer-Gunnink et al., 2017), which may promote high levels of practitioner burnout and decreased quality of care.
DEFICITS IN INTELLIGENCE AND DEVELOPMENT

Individuals with IDD can present with lower intelligence levels as well as deficits in physical and emotional development, which can lead to dependency. They may be dependent on others to help them complete various aspects of their IDLs and IADLs, and in making health-related decisions. Historical events and beliefs have also led to learned dependency in some individuals with IDD; family and caregivers may have repeatedly performed tasks for them, which perpetuates a culture of dependency on others. Changing that culture can be difficult, but research supports that performance “can be improved by occupational therapy interventions in persons with ID, regardless of their underlying capacity (level of ID, awareness of disability)” (Hällgren & Kottorp, 2005, p. 354).

Limitations in intellectual functioning and emotional development can also include decreased comprehension, attention, and memory, and a low frustration tolerance. Decreased understanding during the occupational therapy evaluation and treatment process can manifest as irrational fear, apprehension about interacting with new health care providers or trying new activities, refusal of treatment, and decreased carryover of learned concepts. Additional time may be needed to explain techniques in simpler terms, establish rapport, and help the client with IDD feel comfortable in the long-term-care environment (Simpson, 2015; Sullivan et al., 2011).

Likewise, a short attention span, memory deficits, and a low frustration tolerance can have a direct effect on the therapeutic process. Although these client factors may be unavoidable in this population, treatment sessions should be structured to maximize performance, even when a client presents with these deficits. Altering the treatment environment to minimize distractions, ensuring adequate sensory stimulation, using external memory aids, and providing the client with an appropriate level of challenge may help these clients increase focus and engagement in the tasks presented.

DECREASED COMMUNICATION SKILLS

Decreased communication and socialization skills among those with IDD can have a tremendous effect on the therapeutic process and can be intimidating for those occupational therapy practitioners who lack experience in working with these individuals. Communication deficits can be receptive, expressive, or both, and they can range in severity. Deficits in expressive communication can affect the accuracy of data gathered during the occupational profile, as the client may not be able to convey clear responses. The client with deficits in receptive communication may not understand verbal questions. Thus, the practitioner may rely on family or caregivers to interpret the client’s needs and perceptions. Family or caregivers can also provide insight into the client’s prior methods of communication.

Some individuals with IDD might use augmentative and alternative communication devices or applications, or a picture exchange system—using methods that the client is familiar with can improve communication between the client and care provider. Individuals with IDD may also have delayed response times or respond in ways that they feel will please the questioner; therefore, allowing increased time, asking questions neutrally and in a client-friendly language, and providing pair choices could promote a quality information exchange (Developmental Disabilities Primary Care Initiative, 2011).

CLIENT BEHAVIORS

Research reveals that challenging behaviors are exhibited by 10% to 15% of the population with IDD, and the percentage of challenging behaviors in residential care, including community
living and long-term-care settings, is even higher (Embregts et al., 2009; Emerson et al., 2001). These behaviors can include aggression, agitation, self-injury, verbal outbursts, impulsivity, property destruction, perseveration, or being uncooperative or refusing care (Jahoda & Wanless, 2005). Managing these behaviors while also trying to provide custodial care, therapeutic interventions, or medical procedures for an individual with IDD creates a unique challenge that can ultimately result in stress for the health care provider and disruption in necessary care for the client.

The first step in managing these behaviors is to determine the etiology of the client’s actions. First and foremost, behaviors may stem from unmet basic needs, including hunger, thirst, pain, lack of sleep, or a need for hygiene (Embregts et al., 2009). Addressing these needs first is a foundational step in managing client behaviors. Secondly, clients with IDD can often demonstrate various sensory processing disorders, and they may present with either sensory overresponsivity or underresponsivity.

Behaviors may also occur repeatedly when they are reinforced. Aggression among those with IDD was demonstrated to be a learned behavior, and related to the results that followed (Brosnan & Healy, 2011). Individuals with IDD may exhibit behaviors to gain attention from the staff or other clients. Alternately, if the client reacts aggressively, the practitioner may stop attempting to complete the task, thereby reinforcing the negative behavior.

Behaviors in individuals with IDD may also be directly related to the behaviors of other clients or health care providers. For example, if a client’s roommate yells out repeatedly, the environment might be too stimulating or prevent the client with IDD from gaining adequate sleep to attend to the necessary tasks of the day; the client with IDD may respond with equally problematic behaviors to cope with the situation.

Similarly, a health care provider who approaches the client with IDD abruptly, attempts to complete care quickly, or expresses frustration, might evoke challenging behaviors from the client. This scenario can perpetuate the cyclic relationship in which a client’s challenging behaviors promote caregiver burnout (Jahoda & Wanless, 2005) and further exacerbates the client’s behaviors (Skirrow & Hatton, 2006).

**STRATEGIES FOR MANAGING CHALLENGING BEHAVIORS IN LONG-TERM CARE**

**Behavior Modification Techniques**

Although there is minimal research on using behavioral modification techniques with adult clients with IDD, it has been suggested that behavioral interventions typically associated with treating adults with autism can also be used with this population (Haertle, 2014). Applied behavior analysis is commonly used as a framework for behavior modification with clients on the autism spectrum and clients with IDD. This is accomplished by evaluating a client’s behaviors and using positive and negative reinforcements to get the desired outcome from a treatment session. An example of a positive reinforcement might be giving the client a desired treat when they attempt or complete a task, whereas a negative reinforcement could include simply not giving the client the treat if the task is not attempted or completed.

Another behavior modification technique is using a Functional Analysis of Behavior to develop a functionally equivalent replacement behavior for an undesired behavior (Horner, 1994). The first step in functional analysis is to understand the function of the undesired behavior; for example, is the client acting out in order to be removed from a room or excused from a task that might be overwhelming or difficult? The second step is to replace the undesired behavior with a more appropriate behavior. The third step is to continue reinforcing positive behaviors while ignoring the undesired behavior.

Consider the following example of functional analysis: A 56-year-old male client with IDD admitted to a long-term-care facility had been throwing his meal on the floor or at other clients in the dining room. The OT spoke with the client’s caregivers and determined that the client typically refused to eat any green vegetables. With this new knowledge, staff applied the technique of functional analysis by telling the client that he could remove unwanted green vegetables from his plate and offer them to his tablmates or simply throw them away. Providing these more socially acceptable options to replace the undesired behavior (throwing food on the floor or at others), as well as seating the client in the dining room with other supportive clients, was a client-centered approach to help him control his outbursts.

**Environmental Modification**

Research in occupational therapy supports environmental modifications for addressing behaviors in clients who demonstrate challenging behaviors (Jenson & Padilla, 2017). The fast-paced environment and a large number of clients and health care providers in close proximity in long-term-care facilities may be overstimulating for some individuals with IDD, which may prompt behavioral outbursts.

For example, if a client with IDD is placed near several other clients in a busy therapy department for treatment, they may become overly excited because of an overstimulating environment; this client may respond better to one-on-one sessions in a more secluded area. Decreasing noise levels and treating individuals alone or away from other clients may also decrease unwanted behaviors.

Likewise, an under-stimulating environment could trigger behavioral outbursts, with the reward being greater attention from other clients and health care providers. An under-stimulating environment may also result in increased lethargy and focus on tasks; a client who is under-stimulated might appear unmotivated in their room, but they may have additional motivation when completing a therapeutic activity in the therapy gym, garden, or kitchen, or with a small group of clients.

Environmental modifications could also include personalizing rooms (such as furniture placement, incorporating preferred personal items, altering the lighting), using adaptive equipment (e.g., ambulatory devices, reachers, adaptive utensils), or incorporating environmental cueing (e.g., labelling
and ensure basic sensory needs are met and will no longer and movement can enable tailoring the treatment session to help the individual interpret their environment or in a sensory room or multisensory environment, which individuated and occur in a client's room, as in this example, or in a sensory room or multisensory environment, which can be used as a preparatory activity before other therapeutic interventions. A multisensory environment is a dedicated space that incorporates the use of tactile, visual, auditory, olfactory, and gustatory sensory pathways, along with movement, to help the individual interpret their environment (Lape, 2009).

Sensory Strategies
The presence of sensory processing deficits among individuals with IDD, including autism spectrum disorder, can also lead to behavioral issues. Sensory processing deficits include difficulty receiving, organizing, and regulating sensory input from the environment. These difficulties can hinder emotional regulation, behavioral control, functional task performance, and social relationships (Dunn, 2008). Clients with IDD may present with varying difficulties on the continuum, from hypo- to hyper-responsive to sensory input. A client who is hyporesponsive needs greater amounts of sensory input to function effectively, whereas a client who is hyperresponsive can become overwhelmed with too much sensory input (Dunn, 2008). A client with not enough sensory input could appear lethargic or less engaged in functional activities, or they could demonstrate repetitive behaviors, such as rocking, vocalizations, or touching people and objects (to seek out more input). Conversely, a client who is overstimulated could appear overwhelmed, highly distracted, or agitated and aggressive in an attempt to avoid the overwhelming stimuli.

Understanding and addressing these deficits should be a foundational step before focusing on other occupational therapy goals. For example, a client who is overstimulated (i.e., has a lower threshold for sensory input) might become aggressive when treatment is provided in her room, where her roommate has the television at full volume, the air conditioning on high, and fluorescent lighting on. Treatment in a private space at a comfortable temperature, with soft lighting and ambient music at a low volume, may allow the client to relax, focus on the treatment tasks, and participate to her maximum potential. Sensory-based treatments can be individualized and occur in a client's room, as in this example, or in a sensory room or multisensory environment, which can be used as a preparatory activity before other therapeutic interventions. A multisensory environment is a dedicated space that incorporates the use of tactile, visual, auditory, olfactory, and gustatory sensory pathways, along with movement, to help the individual interpret their environment (Lape, 2009).

Occupational therapy practitioners are educated in assessing and addressing deficits in sensory processing, and research supports the use of individualized sensory-based treatments and environments to promote adaptive behaviors in clients with IDD (Lotan & Gold, 2009). Sensory processing and its resultant behavioral effects can be assessed through observation, client interview, or consulting with the client's previous caregivers. Identifying sensory preferences related to lighting, clothing, soaps/lotions, foods, noise/music, temperature, and movement can enable tailoring the treatment session and ensure basic sensory needs are met and will no longer interfere with other occupational therapy interventions being offered.

Chaining
A common and successful treatment method that is often used with clients with cognitive impairment is “chaining” an activity (Ikiugu, 2007). Forward chaining an activity refers to breaking the task into component parts and teaching those components progressively until the client can complete all the components and the final task. Each component then becomes a stimulus for the next step in the process. In backward chaining, the procedure is reversed; for example, the OT could perform all preceding steps or assist the client to do so, and then the client completes the very last step of the task. Once the client has mastered the last step, another step is added until the client has mastered all steps (Haertl, 2014).

For example, an OT could use backward chaining with a client who is unable to brush their teeth independently. The practitioner would open the toothpaste tube, apply the toothpaste to the brush, place the brush in the client's hand, and move the client's hand to their mouth. The client would then complete the brush movements against their teeth. In the next session, the OT could open the toothpaste and apply toothpaste to the brush, and the client could then move the toothbrush to their mouth and brush their teeth independently. During each session one more step would be added sequentially to the beginning of the process until the client could successfully brush their teeth independently.

Documentation
The initial step in any occupational therapy evaluation is developing an occupational profile (American Occupational Therapy Association, 2014). The occupational profile is used to determine the client's occupational history, interests, values, and needs. This step is vital when developing a plan of care with an individual with IDD in order to understand the client's previous abilities and determine which client-centered interventions might be most appropriate. If the client is unable to participate in the interview, previous caregivers should be contacted; prior caregivers could include family members with whom the client resided or the staff of a group home where the client was previously placed.

Some of the things that are important to gather in an occupational profile are the previous habits and routines of the client. This includes what time the client woke up and their previous morning routine. Determining whether the overarching goal is to return to the previous living situation will help with treatment planning.

For example, if the client is returning to a group home, they may need to have a certain level of functional mobility and self-care prior to discharge from the long-term-care facility. Conferencing with the family or prior caregivers can help the OT determine previous use of adaptive equipment and communication systems. Also, learning the client’s mealtime routines and special dietary needs and preferences could help prevent...
unwanted behaviors. This information should then be passed on to the most appropriate staff in the long-term-care facility to individualize the client’s stay to promote comfort, quality care, and achievement of occupational therapy goals.

It is also important to always document objectively. For example, instead of documenting that the client is repeatedly refusing therapy, document that the client requires maximum encouragement for participation. Gathering information from other facility personnel might be helpful. Perhaps the client is demonstrating improved participation in their self-care during the evening, or is demonstrating improvements with participation in activities. By reviewing documentation from other disciplines, it is much easier to get a more holistic picture of the client’s current status.

As gains can sometimes be small in clients with IDD, occupational therapy practitioners must advocate for these clients to receive the care they need with appropriate stakeholders, including insurance companies, case managers, and facility personnel.

CONCLUSION
As the average life expectancy increases, individuals with IDD are also living longer. Because of age-related changes, acute or chronic illnesses, or the death of a parent, these adults are increasingly being admitted to long-term-care facilities for short-term rehabilitation and long-term placement. By exploring various occupational therapy treatment methods and techniques, occupational therapy practitioners can assist the client and long-term-care staff to create a client-centered approach to gain socially appropriate behaviors and minimize challenging behaviors.

REFERENCES


Final Exam

**Article Code CEA1219**

**Working With Older Adults With Developmental and Intellectual Disabilities in Long-Term Care**

To receive CE credit, exam must be completed by December 31, 2021.

**Learning Level:** Intermediate

**Target Audience:** Occupational Therapy Practitioners

**Content Focus:** Domain: Client Factors; OT Process: Occupational Therapy Interventions

1. The process of transitioning individuals from state-run institutions or asylums to alternative care within the community is best described as what historical event?
   - A. Education for All Handicapped Children Act
   - B. Deinstitutionalization
   - C. Individuals with Disabilities Education Act (IDEA)
   - D. Reconciliation Initiative

2. Which of the following are barriers to addressing occupational therapy goals in adults with intellectual and developmental disabilities (IDD)?
   - A. Practitioners’ stress, fear, and anxiety associated with treating individuals with IDD
   - B. Appropriate expectations for individuals with IDD
   - C. Adequate health care coverage
   - D. Placing an adult with IDD in the same facility as their aging caregiver

3. Sam is a 45-year-old man who was recently placed in an assisted living facility following the death of his parents. He yells, bites himself, and then begins hitting the staff every time they enter his room. What is the foundational step in managing his behavior?
   - A. Use positive reinforcement by giving him a reward every time he is being quiet.
   - B. Place Sam in a room with other clients to determine whether he is under stimulated.
   - C. Use negative reinforcement by removing his television.
   - D. Determine whether Sam’s basic needs are met, including hunger, thirst, pain, lack of sleep, or a need for hygiene.
4. An OT is addressing a self-care goal with Wilma, a 49-year-old client with IDD residing in a skilled nursing facility (SNF). Wilma is working on lower-body dressing. The OT places Wilma’s pants near her feet and slides them onto her legs. Wilma stands up and pulls up the pants. This is an example of what strategy?

- A. Forward chaining
- B. Backward chaining
- C. Learned behaviors
- D. Under stimulation

5. John was admitted into a SNF last week. His medical history includes IDD and anxiety. The staff report that he is cooperative in the morning and during breakfast. However, every time John arrives in the therapy gym, he begins to yell loudly. He doesn’t complete any of his activities or exercises. What may be happening?

- A. John is under stimulated and may need some extra music.
- B. John has limited rehabilitation potential and should be discharged from therapy secondary to plateau.
- C. Because John yells once he arrives to therapy, he may be overstimulated.
- D. John may need to be placed in a group home.

6. Adults with IDD have significant limitations in intellectual functioning and adaptive behavior. Which of the following best describes adaptive behavior?

- A. The correlation between motor planning and physical functioning
- B. The use of executive functioning, including reasoning and problem solving
- C. The awareness of one’s environmental contexts and social cues and norms
- D. The use of adaptive equipment for dressing the lower body

7. Which of the following is an example of an under-stimulating environmental trigger to a behavioral outburst?

- A. The client is completing a seated activity while in a therapy gym with four other clients.
- B. The client is seated in their private room alone.
- C. The client is sharing a room with another client who yells loudly throughout the day.
- D. The client is seated in the lobby near the registration desk.

8. How could an OT adapt an under-stimulating environment to provide an appropriate level of stimulation to increase occupational engagement?

- A. Have a square dancing event and play the music at a level that all clients can hear throughout the activity room.
- B. Take the client on a bus tour of the holiday light display with headphones to limit auditory input.
- C. Complete the therapy session with the client in a quiet room away from distraction.
- D. Turn on the client’s favorite radio station during morning ADLs.

9. Who is the best person to interview to complete the occupational profile for a new client with IDD?

- A. The client
- B. The client’s next of kin
- C. The new roommate
- D. The client and the client’s previous caregiver, if available

10. Sensory processing and regulation involve which of the following?

- A. Receiving, organizing, and regulating sensory input from the environment
- B. Collecting and constructing an organizational framework
- C. Registering hyper-responsivity to irritating stimuli
- D. Regulating all visual, auditory, and proprioception input

11. A new client, Bill, is rocking forward and backward while sitting in the chair, vocalizing sounds, and touching people and the walls. His OT may determine that this is because of what sensory input?

- A. An under-responsive sensory system attempting to gain extra input
- B. An over-responsive sensory system using self-regulation
- C. Proprioception and primitive reflex integration
- D. Joint contractures and limited active range of motion

12. What are the three steps in completing a Functional Analysis of Behavior?

- A. Understand the desired behavior, replace the undesired behavior, and reinforce appropriate behavior.
- B. Discipline, reinforce, repeat.
- C. Positively reinforce appropriate behavior, negatively reinforce undesired behavior, and practice token economy.
- D. Reinforce appropriate behavior, understand the desired behavior, and replace the undesired behavior.

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