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Day Programming for Aging Adults with Intellectual Disabilities: A review of what is and what should be

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DAY PROGRAMMING FOR AGING ADULTS WITH INTELLECTUAL DISABILITIES:
A REVIEW OF WHAT IS AND WHAT SHOULD BE

by

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B.A., Northern Illinois University, 2003

A Research Paper
Submitted in Partial Fulfillment of the Requirements for the
Master of Science

Department of Rehabilitation
in the Graduate School
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RESEARCH PAPER APPROVAL

DAY PROGRAMMING FOR AGING ADULTS WITH INTELLECTUAL DISABILITIES: A
REVIEW OF WHAT IS AND WHAT SHOULD BE

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Kelly Norris-Evans

A Research Paper Submitted in Partial

Fulfillment of the Requirements

for the Degree of

Master of Science

in the field of Behavior Analysis and Therapy

Approved by:

Jonathan C. Baker, Chair

Graduate School
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AN ABSTRACT OF THE RESEARCH OF

Kelly Norris-Evans, for the M.S. degree in Behavior Analysis and Therapy, presented on the 10th of April, 2012, at Southern Illinois University Carbondale.

TITLE: DAY PROGRAMMING FOR AGING ADULTS WITH INTELLECTUAL DISABILITIES: A REVIEW OF WHAT IS AND WHAT SHOULD BE

MAJOR PROFESSOR: Dr. Jonathan Baker

The life expectancy of individuals with intellectual disabilities has risen with the improvement of medical technology and improved access to health care, which has resulted in a new need to provide supports to these individuals in their later years. Presently there is no clear model on how to provide these services to this growing population. Therefore, the purpose of this paper is to examine differences in nursing home and Intellectual Disability services in an effort to determine suggestions on best practices for programming for aging adults that have intellectual disabilities.

DEDICATION

I would like to dedicate this research paper to my husband, Paul. Your love and constant reassurance that I could do this is what has gotten me through. Having our sweet daughter, Avery, born in the middle of all this wasn't exactly in the plan, but our faith and our God got us through. I am so grateful to you and Logan for moving your lives back to Chicago to start a new life with me.

I would also like to thank my parents, Jim and Barb Norris, and my sister, Tracy Mick, for your loving support. Thank you for believing in me and encouraging me to keep going. I love you all.

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The life expectancy of a typically developing child born in 1900 was only 47 years old. A little over a hundred years later that number has jumped by 32 years to 79 years old. Likewise, the average life expectancy of people with developmental disabilities has also improved dramatically. In 1900 a child born with an intellectual or developmental disability had a life expectancy of 19 years old. That number increased to 66 years of age in 2006 (Center for Disease Control and Prevention, 2009; Bittles, Petterson, Sullivan, Hussain, Glasson & Montgomery, 2002). This number is smaller for those individuals with Down Syndrome because they age more rapidly than the general population or others with ID/DD (Yang, Rasmussen, & Friedman, 2002). The shorter life expectancy is also true of people with cerebral palsy, epilepsy, multiple disabilities, profound intellectual impairment, and individuals who cannot walk.

There are two major factors that have contributed to the increase in life expectancy. One factor is that there have been vast improvements in access to health care (Clearbrook, 2010). Many people currently working in the field would argue that the access to health care for people with ID/DD is still poor, but nevertheless, it has improved in the last several decades. The second factor is improvements in public health including better sanitation and the discovery and widespread availability of vaccines and antibiotics reduced death from widespread diseases such as polio, influenza, and tuberculosis. These improvements have narrowed the gap between the general population and the ID/DD population so much that the leading causes of death for both of these groups are now the same and include heart disease, cancer, and respiratory disease (Janicki, Dalton, Henderson & Davidson, 1999).

As these phenomenon have occurred, it has brought new challenges to agencies and providers that service the aging ID population. Historically agencies and providers did not have to focus on how to serve aging adults because the adults weren't living long enough to get into

their ‘senior’ years. That has now changed and agencies have to address the needs of the growing senior population that they serve (Braddock, 1999). The time to strategize and plan is now, as American Association on Intellectual and Developmental Disabilities (AAIDD) has projected that by the year 2030 there will be several million adults with intellectual disabilities that are considered seniors.

Most research about caring for aging people is based in nursing homes. Very little research has been done to look at how agency providers (residential/vocational) can provide quality services to their aging adults with the goal being that the person can ‘age in place’ in the residence/environment that they have been living at for most of their adult years. Although some researchers have noted the need to address this, very little research has been done to lay out specific recommendations for this growing population (LeBlanc & Matson, 1997).

The purpose of this paper is to look at: (a) the adjustments that need to be made to the environment/physical plant to foster the most independence and success in aging adults with ID, (b) models of care that will help promote healthy aging and a positive quality of life in the aging years, (c) training staff to address and support the needs of our aging population with ID, (d) addressing problem behavior in the aging ID population, and (e) the best model of care to use with aging adults with ID. Each of these five areas will be reviewed by first noting current practices for typically developing aging populations in nursing homes, followed by practices for adults with intellectual disabilities. Finally, we will provide suggestions for aging ID populations.

Environmental/Physical Plant Considerations

The first area of importance for aging adults is the environment or physical plant of the space they will be in. The environment or physical plant includes the general design of the space,

but also takes into account safety concerns. Safety concerns will be discussed at length due to the significant consequences that can occur for aging adults if they are in an unsafe environment.

Nursing Home

The over 1200 nursing homes in Illinois are regulated by agencies at the state and federal levels, including the Illinois Department of Public Health (IDPH) and the U.S. Department of Health and Human Services' Centers for Medicare and Medicaid Services (CMS). There are over 1500 state and federal standards that nursing homes have to be in compliance with (taken from <http://www.idph.state.il.us/healthca/nhregulate.htm>). The Bureau of Long-term Care is responsible for making sure that nursing homes comply with the provisions of the state Nursing Home Care Act.

Detailed administrative codes are in place that clearly identifies building requirements for nursing homes. The administrative code can be found on the Illinois General Assembly webpage. For example, according to subpart N of the Administrative Code (Title 77, Chapter I, Subchapter c, Part 300, subpart N), the combined area of dining and activity rooms cannot have less than 25 square feet per resident. There also has to be a minimum of one bathroom for every 10 resident beds on each floor of the nursing facility. Dimensions of shower spaces and bathroom spaces are identified, as well as specific dimensions required for those nursing home residents that have physical disabilities. In addition, although Illinois law does not specify a particular temperature that needs to be maintained in nursing homes, federal laws mandate that it has to be between 71-81 degrees Fahrenheit.

The administrative codes also address several areas related to safety. Handrails must be provided on both sides of all corridors and ramps that are used by residents. Grab bars must also be provided for all toilets, showers and tubs that are for resident use. The ends of the handrails

and grab bars must return to the wall instead of being open ended. The main entrance and exit doors must swing outward. Exterior doors also have to be equipped with an alarm that can alert staff if a resident leaves the building. The items on lighting are less concrete and only state that a resident's room should have 'general lighting' and that a reading light (table lamp) should be provided for each resident. There should be sufficient lighting in the dining room and recreation areas. The codes also discuss flooring guidelines which state that the floors should be smooth and free from cracks so that they can be easily cleaned. Door thresholds also have to be flush with the floor to facilitate the use of wheelchairs and walkers and prevent tripping hazards. My research has not turned up any clear indication as to whether there are safety guidelines for the type of furniture (tables and chairs) that nursing homes should provide to their residents. Another topic not addressed in the administrative code is how the decorating of a space (paint colors, patterns, etc.) can affect the overall functioning and success of an older adult.

Programs for Adults with ID

Adults with ID that live in residential placements most often attend a day program site each day of the week. This schedule would mimic that of a 'typically developing' adult and their regular work schedule. Depending on the interests of the individual, they may participate in paid work opportunities (either in the community or in a sheltered workshop) or other leisure activities (art, recreation, horticulture, etc.).

As mentioned previously, due to the low life expectancy rates of adults with ID, agency providers did not have to cater to an aging population in their programming efforts. There was a relatively narrow age range that needed to be served and therefore specialization was not required. Work and leisure areas were designed without taking into account the future need to provide services to a large elderly population. This resulted in standard work spaces that met the

needs of adults, but that are no longer meeting the needs of our aging adults. Spaces that were once adequate are now lacking sufficient support (lighting, contrasting colors for work space, comfort of chairs, etc.). Workshops also have to be in compliance with requirements set forth by the American's with Disabilities Act.

Many sheltered workshop areas have a warehouse style appearance, with white or gray walls and concrete floors. These areas may appear institutionalized and sterile. Long work tables and plastic chairs are the norm. Plastic chairs are often used to allow for easy cleaning and portability. They also tend to be more economical and hence more easily replaceable. Lighting in most of these warehouse style settings are the typical fluorescent bulbs. These again are an inexpensive choice and do not require frequent replacement.

Recommendations for Programs for Aging Adults with ID

The aging related changes that adults with ID have to adapt to are vast and include changes to the senses of sight, hearing, taste and smell; decreases in somatosensory perception; loss of strength and flexibility; and declines in posture, balance and awareness of spatial positioning. When planning a program for aging adults with ID, those factors should be taken into account through careful lighting design, acoustic control, and attention to surface color and contrast. The Grace Manual (Clearbrook, 2011) provides a checklist of design guidelines that outline issues to consider in building design and layout.

In the area of safety, there are several areas that should be considered. One of the most frequent causes of injury with aging adults is falling. There are multitudes of flooring surfaces available on the market today, but not all would be a good choice for elderly people. If a space has carpet, the carpet should be in good condition and not have any tears or creases. Tears and creases in the carpet are serious trip hazards fall all of our clients, but especially for the elderly.

Short-strand carpet, such as berber, would be safer than a long-stranded carpet such as shag. Carpet of any sort, however, can make it difficult for people who utilize walkers or wheelchairs. On the flip-side of that, carpet can help soften the impact when someone does fall down. Throw rugs or other decorative flooring mats should be removed from the area where programming will be occurring. If at all possible, flooring that is not carpeted should be of a slip-resistant variety and also non-reflective and solid in color. Research by Hussian & Brown (1985) indicates that floor patterns and even reflections can affect behavior among individuals with dementia. Contrast is also extremely important for older adults and having a strong contrast between the wall color and flooring will help the older adult differentiate spaces (Van Hoof, J., Kort, H., Van Waarde, H., & Blom, M., 2010). All hallways and staircases that will be used should have handrails. The beginning and end of the handrails should return to the wall. There are also specialty handrails that are designed in such a way that a persons' hand cannot slip between the rail and the wall if they were to fall, thus preventing a broken wrist or other injuries. Another consideration would be installing colored, reflective, slip-resistant strips on stairs or any other area where the flooring type or pitch is about to change.

Lighting is also an area of importance for safety. According to Pirkle (1995), older adults need about 3 times as much light as a 20 year old. An exact recommendation in regards to wattage is difficult to determine due to differences in natural light in the area and other factors. However, it should be kept in mind that too much light can create uncomfortable eye glare for an older person. Too little light can also be dangerous as it can create shadows and result in gait instability, as well as fear for the older adult. The environment should be lit in a way that supports ambulation and is adequate for the provision of services. If windows are present in the programming area, there should be window treatments that minimize glare.

Bathrooms are areas that are often overlooked in design. They are generally very sterile looking, with the colors white or beige covering every surface. This color scheme is often chosen because it gives a clean appearance, however, little or no contrast makes these spaces very dangerous for older adults. Bathrooms can be made safer for older adults but installing colored toilet seats and/or sinks (Van Hoof et al., 2010). This will allow an older adult with declining vision to easily determine where they are headed for. Another safety feature would be to have raised toilet seats with arms. This protects older adults that have depth perception issues from misjudging the space and can prevent falls. Grab bars should also be present by toilets and bathtubs/showers. Large, colorful signs should be affixed to the door of bathrooms indicating if it is a male or female bathroom. This will limit confusion on the part of the older adult. It has also been suggested that removing the typical small garbage bins from the bathroom will eliminate the chances of a confused client using the garbage as a toilet (Van Hoof et al., 2010).

The kitchen and dining room is another area of programming that should be considered when planning a program for older adults. Lack of contrast in these areas can lead to confusion and even refusal to eat in older adults with ID. Laying the table in contrasting colors will help the older adult to differentiate between items on the table. For example, if the table is white, the plate should be either a darker color or if it is a lighter color, it can have a dark colored band around the edge of the plate. Likewise, if the table is dark in color, the plates should be a lighter color that will stand out. Having a contrasting color band around the edge of a table will also help the older adult with ID to understand where that surface ends. This can help prevent the dropping of plates, silverware and cups off the table. Other useful items for older adults with ID, which would be determined on a person by person basis, are large handled utensils, divided scoop dishes, weighted utensils and covered cups. Adjustable height tables are recommended so that

the needs of all clients, whether they are able to ambulate on their own or use a wheelchair, can be supported. Chairs with arms and no wheels are also safest, to decrease the likelihood that a client will fall out of their chair. (Clearbrook, 2010.)

Activity rooms or other areas that older clients will be spending a significant amount of time should have several things in common. The first and perhaps the most important is comfortable seating. The chairs should have several features including arms, no wheels, and waterproof cushioning for comfort. Providing cushioning will make the chairs more comfortable for the older adult who may be experiencing arthritis or other health issues that cause physical discomfort. To protect the integrity of the chairs, they should be covered with waterproof fabric to prevent the occasional spill or incident of incontinence from ruining the chair. They should also support good posture. Alternative seating should be available for some forms of programming, such as recliners (Clearbrook, 2010). This will be discussed further at another point in our discussion. There are many types of adjustable height tables that are available that are suitable for many different types of programming tasks. A table that can be used for multiple purposes is of great benefit to an older adult. For example, an adjustable height table can be set at standard height for game playing, but then later in the day lowered so that a group of elderly women can sit around it and use it as a coffee table to have their 'girl time chats.' Having these adjustable height tables allows for many forms of programming to take place in the same room. As mentioned earlier, care should be taken with lighting (natural and indoor) and contrasting colors between the floors/walls and doors/doorways. All areas that will be used for programming should be free of debris that could be a potential trip hazard or other safety hazard. Automated doors are suggested to help maintain the independence of the older adults that are

ambulating with the assistance of a walker or wheelchair. Also, the thresholds from room to room should be flush with the floor so that there is nothing the older adult can trip on.

Models of Care

The model of care, or philosophy of care, differs greatly between nursing homes and facilities that provide services to adults with ID/DD. In previous years, nursing homes were known to follow the medical model of treatment where the focus was on the clinical condition, not on the person themselves (Pratt, 2004). In recent years, nursing homes have moved towards a more multidisciplinary approach which includes supporting the persons' medical and social needs. Individuals reside in nursing homes for a multitude of reasons, including medical, financial and social needs. The multidisciplinary or holistic approach allows the nursing home to support an individual in all these areas. Regardless of this change in approach, it still stands that in general nursing homes are thought of as places that individuals go when they are seniors and entering the last years of their life. Approximately 90% of consumers in nursing homes are 65 years or older (Pratt, 2004). Nursing homes also may have special care units within the nursing home that focus on specific areas such as Alzheimer's disease, Mental Health or Mental Retardation and Traumatic Brain Injury. Nursing homes can also group people by age, since health issues such as Traumatic Brain Injury are not specific to a certain age group. To summarize, individuals that are admitted to nursing homes have disabilities resulting from either medical or physical conditions which require the support of a medical facility. Thus, the staff usually follow a caregiver type model of care.

Day programming for individuals with ID/DD typically focus heavily on providing individualized support to clients in an effort to rehabilitate. While it is accepted that there is no 'cure' for an intellectual disability, day programming for individuals with ID/DD focuses on

teaching functional skills to the individual in an effort to increase their independence and help them achieve their goals. Like nursing homes, day programs for individuals with ID/DD support a wide range of individuals with differing needs. Individuals usually transition from high school and into a day program around the age of 21 or 22 and can continue receiving day program services throughout the rest of their lives. The individuals served vary in their diagnoses and support needs, but almost always have a mental retardation diagnosis. The severity of their disability (mild, moderate, severe, profound) will determine the type of program they participate in. One set of researchers has determined through their study of 59 older people living in different types of homes that older people with an intellectual disability experienced better quality of life outcomes in terms of participation in a meaningful activity and community access when they lived in homes and received services for people specifically with intellectual disabilities (Higgins & Mansell, 2009). It is important for further research to be done in this area so that all services for older adults, disabled or not, will provide a high quality of life for its' consumers. Some of the specific areas that nursing homes and day programs can vary are programming, staff training/ratios and intervening with skill deficits/excesses.

Programming in Nursing Homes

Nursing Homes are primarily focused on the medical needs of their clients while their daily programming is secondary. Medical needs encompass several areas including actual care provided by the nurses as well as assistance with activities of daily living (ADL's) by the certified nursing assistants (CNA's). Providing activities that the clients enjoy is extremely important, as the prevalence of depression among nursing home residents is known to be high (up to 40%) (Godlove et al., 2000). Active engagement is also important for individuals with dementia. Studies have found that nursing home residents with dementia spend the majority of

their time engaged in no activity at all, with unstructured time accounting for two-thirds of the day or more (Lucero, Pearson, Hutchinson, Leger-Krall, & Rinalducci, 2001). Inactivity in nursing homes is a long-standing issue as evidenced by studies dating back to 1974 that showed that extended periods of inactivity and nonparticipation lead to loss of verbal and self-care skills (McClannahan & Risley, 1974). Most often the activity calendar that is put out each month at nursing homes by the activity department is a list of activities that the residents can elect to attend or not attend. Essentially, the residents have the option of staying in their room all day by themselves or the option of attending one of several activities which are usually held in a specific room of the nursing home. The activity time each week should total not less than 45 minutes multiplied by the number of residents in the facility. For example, if a nursing home is a 100-bed facility, there must be 75 hours of activities in that week's schedule. These hours include actual activities, but also the time spent planning and directing the program.

According to subpart N of the Administrative Code, facilities need to provide an ongoing program of activities to meet the interests and preferences and the physical, mental and psychosocial well-being of each resident. These interests and preferences are determined by an assessment that includes the following areas: background information (educational level, cultural issues, spiritual needs), current functional status (communication, physical status, cognitive abilities, behavioral issues) and leisure functioning (attitude toward leisure, knowledge of activity skills, social interaction skills, activity interests). Once the assessment is complete, the activity department staff will develop a plan of care that addresses the needs and interests of the residents, including activity goals and interventions.

Subpart N of the Illinois Administrative Code goes on to state that each facility will provide a specific, planned program of individual and group activities that are aimed at

improving, maintaining, or minimizing decline in the resident's functional status and at promoting well-being. Activities must be offered daily and should reflect the schedules, choices and rights of the residents (e.g., morning, afternoon, evening and weekends). The activities should be multifaceted and should be adapted to the individual resident's capabilities.

Suggestions of types of activities include: physical activity (exercise, fitness, adapted sports); cognitive stimulation/intellectual/educational activity (e.g., discussion groups, reminiscence, guest speakers, films, trivia, quizzes, table games, puzzles, writing, spelling, newsletter); spiritual/religious activity (e.g., religious services, spiritual study groups, visits from spiritual support groups); service activity (e.g., volunteer work for the facility, other individuals and/or the community); sensory stimulation (e.g., tactile, olfactory, auditory, visual and gustatory); community involvement (e.g., community groups coming into the facility for intergenerational programs, special entertainment and volunteer visits; excursions outside the facility to museums, sporting events, entertainment, parks); expressive and creative arts/crafts (adapted to the resident's capabilities), music, movement/dance, horticulture, pet-facilitated therapy, drama, literary programs, art, cooking; family involvement (e.g., correspondence, family parties, holiday celebrations, family volunteers); and social activity (parties and seasonal activities). This is an impressive list by any standard, which leads me to wonder why the rate of depression in nursing homes would be so high if all of these individualized activities are taking place.

Programming for Adults with ID

Programming for adults with ID is supposed to center around an Individual Support Plan (ISP), sometimes also referred to as an Individual Treatment Plan, which is created with the assistance of that individual and their interdisciplinary team. The plan is meant to help that individual work towards their goals. Day programming goals are a part of the overall ISP and a

large part of how many adults with ID spend their day. Day programming often involves vocational work combined with activities. The ratio of work to activities depends on the severity of each person's disability. For example, a client that has significant impairment in the area of impulse control or attention is unlikely to be able to attend to a paid work activity for several continuous hours. They may be better served by a split schedule that allows them to move back and forth between work and leisure activities. Choosing a split schedule can decrease the frustration that can come from doing a single activity for prolonged periods of time.

Most day program locations are open Monday through Friday and have operating hours between 9-3p.m. Programming can fall into four general categories: on site paid work opportunities, community employment, prevocational programming and extracurricular classes. On-site paid work opportunities are those that are brought to the day program location for the clients to do on-site. These could be hourly jobs or piece rate work, where the client gets paid per 'piece' of the job they do. These types of jobs are common in day program locations. Community jobs are those that are based in a different location from the day program site and can be the same jobs that typically functioning adults may compete for. The individuals who work in the community may have the support of a Job Coach that is at their job with them, while others are completely independent with their community job. Community jobs can be at a plethora of places, including fast food restaurants, grocery stores and hospitals. Prevocational programming is for individuals that are unable to participate in paid work opportunities at this point in their life due to their intense support needs. Prevocational programming will focus on teaching clients the basic skills they need to be able to do paid work at some point in the future, along with other skills that may be lacking, such as daily living skills, community integration, and social skills. An example of a prevocational task could include sorting like objects, sorting

by color, or small assembly jobs. A newer trend that is emerging in day programming is the area of extracurricular classes. These are activities or classes that individuals can participate in throughout their work week to help diversify their work day. Some examples include jewelry class, horticulture therapy, recreation (sports, gym, swimming, Special Olympic preparation), and Art (Studio art, media art and textile art). During the annual process of preparing for an individual's ISP (and more often as necessary), the individual and their guardian should have the opportunity to express what their interests are for day programming. The interdisciplinary team should be able to come together and create a day programming schedule that meets the vocational and social needs and preferences of the individual.

Recommendations for Programming for Aging Adults with ID

Programming for aging adults with ID should be robust and an exciting adventure that the individuals will be eager to participate in. For many of the aging individuals with ID, participating in a Senior Program will be the closest they will ever come to retirement and the goal should be to help them enjoy their aging years. This can be a difficult transition for many due to the number of years they have spent in typical day program settings. Routine is a comfort to individuals with ID and changing the routine can be a challenge at first. This challenge is another reason why dynamic and fun programming is so important to helping our aging individual's transition successfully into a more relaxed, less work-driven schedule.

Gerontology research has repeatedly shown that a busy, active life style for senior adults is the best way to maintain mind, body and spirit functioning (Clearbrook, 2011). Gone are the days when the services provided to aging adults with ID centered around just keeping them safe, and often consisted of them watching television all day long with the guise of resting and participant choice. These excuses are no longer acceptable and there is mounting research to

indicate the exact opposite to be true (Engelman, Altus, & Mathews, 1999; Yan, Wilber, Aguirre, & Trejo, 2009). Aging adults with ID that live a sedentary lifestyle will quickly lose their fine and gross motor skills which could eventually preclude them from being able to participate in the type of programming they rightfully deserve.

The research done by the Grace Project (Clearbrook, 2011) has identified seven domains that will help support well-rounded services for aging adults with ID. They include: orientation, memory and reminiscence, communications, health promotions and wellness, recreation and leisure, activities of daily living and spirituality. Each of these domain areas can be customized to support the varied needs of the participants in the program. These seven domains are the framework within which specific activities are created to engage the participants in.

Activities can be catered to meet the needs of all individuals. When an activity appears to be too difficult or complex for an individual, the next step should be to look at what foundational skills need to be present for the individual to be successful at the activity. The teaching of that skill then becomes the focus of the activity. Activities should be engaging, relevant and meaningful to the individual. As with all activities, the staff that are assisting need to be cognizant of the effectiveness of the activity so that adjustments can be made when necessary. If the activity is proving to be too easy or too difficult for the group, a backup plan should be readily available to either assist in scaling back the activity so that it is more simple or adding another step to make it more challenging. The backup plan should be decided before the activity begins so that the staff are able to adjust immediately to the needs of the group.

Following a weekly preplanned schedule is a wise choice and allows for better services through more organized and well planned activities. While using a schedule is best practice, there also has to be flexibility within the schedule for changes that may occur. This is another

instance when having a backup plan is helpful. For example, on a day that there is outdoor gardening scheduled, it would be wise to also have a backup plan for an indoor activity in case it were to rain. Schedules for adults with disabilities should be built on thirty minute time blocks. This allows flexibility to change activities in accordance with the attention span of the participants. The thirty minute blocks can be combined into larger blocks for activities that take longer. See figure 1 for a sample weekly schedule.

Figure 1.

Sample Weekly Schedule

Day: Time:	Monday	Tuesday	Wednesday	Thursday	Friday
9:00am	Orientation	Orientation	Orientation	Orientation	Orientation
10:00am	Communication: Reading Circle	Memory Skills: Concentration	Health: Yoga	Rec/Leisure: BINGO	Memory Skills: Memory Books
10:30 am	Rec/Leisure: Scavenger Hunt	Communication: Sign Language	Memory Skills: Reminiscing	Communication: Social Skills	ADL Skills: Dressing
11:00 am		ADL Skills: Meal Planning	Rec/Leisure: Computer Skills	Memory Skills: Object Identification	Spirituality: Volunteering
11:30 am	Lunch Quiet/Rest Orientation				
1:00 pm	Rec/Leisure: Horticulture	Rec/Leisure: Music	Rec/Leisure: Bowling	Rec/Leisure: Bean Bags	Communication: Community Safety
1:30 pm		Health: Dancing			Rec/Leisure: Community Outing
2:00 pm	Memory Skills: Scent Identification	Rec/Leisure: Arts & Crafts		Health: Nature Walk	
3:00 pm	Spirituality: Meditation			ADL Skills: Hygiene	

The Grace Project recommends quarterly assessments in order to capture the needs and interests of each individual, as the needs of the aging population can change rapidly. The assessment should include current medical information, background/social history, current abilities, dislikes, interests and hobbies. Schedules should be designed so that there is a natural flow to the activities. Orientation activities are designed to help people orient to the areas of person, place and time while at that same time mentally and physically preparing themselves for upcoming events (Clearbrook, 2011). Orientation activities are especially helpful at major transition periods throughout the day, such as start of the day, lunch time, and end of the day. Staff must be prepared to assist during these transition periods to make the process as smooth and simple as possible for the participants.

Transitions can be difficult for people with ID and environmental factors can add to the stress during transition periods. Individuals with ID need to be reminded frequently when a transition period is coming (moving to a different space, preparing to leave the building at end of day, etc.) to decrease their confusion and stress. Some seniors with ID can benefit from the use of a picture schedule.

Staff Training and Ratios

Types of Staff in Nursing Homes

Nursing homes require people from many different occupations to successfully run their business. Typically, nursing home staff include nurses and certified nursing assistants (CNA's). Nursing homes require that a licensed nurse be on site during every shift. Government regulations specify the number of staff on duty on each work shift and the mix of personnel categories making up that staff (Pratt, 2004), though CNAs make up the largest proportion of

staff in nursing homes. CNA's are responsible for almost all direct resident care that is not provided by a specialist. This includes assisting residents with all aspects of daily living such as bathing, toileting, dressing and eating. Many other specialists provide services on a limited basis in nursing homes, including physicians, dieticians, social workers and therapists (physical therapy, occupational therapy, psychotherapy).

Staff ratios in nursing homes

Staffing for nursing homes is addressed in Section 300.1230 of the Administrative Code and involves a complex formula that takes into account the level of care each resident in the nursing facility needs. For example, residents that require skilled nursing care are allotted 2.5 hours of nursing-personal care each day. Residents that are determined to need intermediate nursing care receive 1.7 hours of nursing/personal care each day and a resident that needs only light intermediate care will receive 1 hour of nursing/personal care each day. A licensed nurse must provide 20% of that time to the resident. The remaining 80% of personal care time can be divided between the CNA's or licensed nursing personnel, as long as it is documented as such (Illinois General Assembly, 2012).

The Illinois General Assembly provides an example on its website (www.ilga.gov) that involves a 100 bed facility with 25 people falling into the skilled nursing category, 50 in the intermediate category and 25 in the light intermediate category. Following their formula, on a regular 3-11pm shift, the facility would require there be 1.5 licensed nurses and 6 CNA's available. This amounts to an overall staff to client ratio of 13:1.

Staff Training in Nursing Homes

Nurses have to be licensed in order to practice in nursing home facilities. Most reputable nursing programs provide at least one course that focuses specifically on the aging population.

For example, St. Xavier University is a popular university in Chicago known for its nursing program. According to the University website, St. Xavier has a specific course called Nursing Care of the Older Adult (NURS 347) that focuses on teaching nurses how to provide holistic care to older adults.

CNA's are placed on the Nurse Aide Registry when they have successfully completed a training program that is approved in accordance with the Long-Term Care Assistants and Aides Training Programs Code (77 Ill. Adm. Code 395) and had met required background checks. According to the Illinois Department of Public Health website, CNA training programs in Illinois require 88 hours of class/lab time and 40 hours of hands on experience in a hospital or long term care setting. The areas that are studied include anatomy, physiology, basic nursing skills, personal care skills, resident's rights and mental health needs. CNA's can work in a variety of medical fields including hospitals and nursing homes and therefore their training program is not specific to working with the elderly population. This would mean that CNA's would need to receive more in depth training specific to the elderly population on the job if they were to be successful and considered adequately trained to support the needs of the elderly people that were entrusted to their care.

Due to the medically focused training that CNA's receive, their concentration is primarily on completing their work tasks (bathing, feeding, toileting the residents) in the most efficient manner possible. Since the CNA's often have a large number of residents to care for, this can often mean that the CNA does the task for the resident instead of helping the resident do the task themselves. This follows the caretaker model of care that most nursing homes have. Unfortunately, providing too much assistance for the residents can increase resident dependence on the staff and in the long run make the CNA's jobs more difficult. Providing training to CNA's

on prompting methods can actually save them time assisting with these activities of daily living. One study by Engelman, Altus, Mosier and Mathews (2003) provided a thirty minute training for several CNA's on how to use the system of least prompts (SLP) during their morning dressing routines.

The SLP is a prompting system that uses less intrusive prompts (e.g., verbal, gestural) before providing physical guidance or full assistance (Winborn, Wacker, Richman, Asmus, & Geier, 2002). The point of the SLP is to promote independence in the residents by encouraging them to complete as much of the task as they can on their own. As stated above, this can be difficult for a CNA to do because it would appear as though this format would require the CNA to spend more time with each resident. However, the results of the Engelman et al. (2003) study on the SLP with dressing routines showed that using the SLP did not increase dressing time. Residents had spent a mean of 6.7 minutes dressing during baseline compared to 6.5 minutes after the SLP training for staff. The focus staff should have for aging adults should be to promote or maintain their independence as long as possible by providing them with support instead of just taking care of them in the name of efficiency.

In-service training is often provided and required for CNA's and can help them develop their skills in the care, guidance and management of client behavior such as self-care, communication, language, vocational skills, or prosocial behavior. Burgio et al. (1990) showed that staff training programs have successfully increased staff performance in areas including instruction giving, prompting and reinforcing for many clients in areas including nursing homes. Also, adding on-the-job performance feedback to basic analog training was shown to be a more effective training method than basic analog training alone (Arco & Du Toit, 2006).

One variation on traditional nursing homes that is becoming more popular is the Green House (GH) model. Green House homes are meant to deinstitutionalize long-term care and create a supportive environment for aging adults by doing four main things that are different than nursing homes (Sharkey, Hudak, Horn, James & Howes, 2011). The first difference is that GH homes are self-contained residences for nine to 12 older adults that each have their own private room and bathroom. The physical plant is designed as a regular home would be, with a large great room, large dining room and a walk-in kitchen. The second difference is the redesigned role of the CNA into a position called Shahbazim. The Shahbazim are specially trained universal workers who manage the duties of a CNA plus additional home management responsibilities such as personal care, meal preparation, housekeeping, laundry and activities (Sharkey et al, 2011). The third difference is that the Green House model uses a self-managed team approach where the Shahbazim work as a self-managed team and receive coaching and supervision from a guide. The final difference is that the support team (nurses, social workers, therapists, nutritionists and medical director) partners with the Shahbazim to provide quality care to the clients. This is different than the CNA model where the support team more often tells the CNA's what to do instead of working with them as a team. The results of the Sharkey et al (2011) study showed that the GH model allows for expanded responsibilities of CNA's in indirect care activities and more time in direct care activities and engaging directly with residents.

Types of staff in programs for adults with ID

Direct Service providers (DSP) are the front line staff in programs for adults with ID. These DSP's most commonly take the form of Job Coaches or Developmental Trainers who provide support to individuals in the vocational or prevocational setting. There are also supervisory staff or managers over the individual vocational programs. The supervisory staff are

responsible for making sure that the vocational program is run safely and that program outcomes are met. Often there are also case managers, who are Qualified Intellectual Disability Professionals (QIDP), who have a caseload of individuals they are responsible for writing goals for and providing case management support for in the day program setting. As with nursing homes, there is also a whole team of specialists that are also a part of the care for each individual, such as nurses, nurse practitioners, dietitians, physical therapists, occupational therapist, and psychiatrists.

Staff Ratios in programs with adults with ID

Staff ratios in programs for adults with ID are based on Rule 119, set forth by the Illinois Department of Human Services (DHS). Currently, the ratios are dependent on the degree of deficit in adaptive behavior that each individual has. For individuals with mild deficits in adaptive behavior, the staff to client ratio is 1:10. For individuals with moderate deficits in adaptive behavior, the staff to client ratio is 1:8. Finally, for individuals with severe or profound deficits in adaptive behavior, the ratio is 1:5 (Illinois General Assembly, 2012). DHS's calculation of provider costs is based on these ratios, but they are flexible in allowing the agency to group individuals to best meet the individual's needs. Agencies can all apply for increased staffing for individuals who have pervasive medical or behavioral needs that necessitate specialized care for the safety or well being of the individual or others.

Staff Training in Programs for Adults with ID

According the Illinois DHS website (www.dhs.state.il.us), the training program required by DHS to become a certified Direct Support Person (DSP) includes six modules on the following topics: Introduction to Developmental Disabilities, Human Rights, Abuse and Neglect, Human Interaction and Communication, Individual Service Plan Development and

Implementation, and Basic Health and Safety. Supplementary classes are often provided that are individualized to each agency. Some of these supplementary classes may include Bloodborne Pathogens, Safety Issues, Non-violent Crisis Intervention training, DCFS Rules and Regulations and CPR/First Aid. DHS also mandates that a DSP receive 80 hours of on-the-job training with their supervisor. Their supervisor has to work through a series of on-the-job training modules with the new staff person, sign off that the staff person understands the concepts, and provide this documentation to DHS. The DSP can then be placed on the DSP registry.

DSP's may receive ongoing training during their career in the form of in-service trainings or refresher classes on topics they have already been trained on. Nurses may come to do training on a specific individual that is having health issues that have necessitated some medical intervention that will affect their day program setting. Many agencies that provide support to individuals with ID have behavior analysts on staff. This is a fairly new trend and speaks to the realization of service providers that they need to have specialized staff available to devote all their time to the development of behavior support plans that can help the individuals to be as successful as possible. The behavior analysts should then be providing training to the DSP's on the behavior plans and how to implement the intervention strategies within the plan. Being able to successfully carry out the behavior support plan can often determine how successful an individual with frequent problem behavior will be in the vocational placement.

Recommendations for Staff Training/Ratios for Aging Adults with ID

The Grace Project (2011) provides a comprehensive training on how to provide supports to older adults with ID. The curriculum includes six modules that focus on the following areas: Aging Well; Alzheimer's and Dementia; Programming and Health Promotion: The Physical Aging Process; Programming and Health Promotion: The Spiritual, Social, and Emotional Aging

Process; End of Life/Grief and Loss; and Caring for the Caregiver. The content areas just mentioned provide a robust training program that will give staff a holistic understanding of the aging adults they are serving. The modules also provide a chance for experiential training of the staff. Experiential exercises can be very effective for staff because they show them how it would feel to be the aging adult with ID that they are providing services to. For example, if you were to use safety goggles with Vaseline smeared on the lenses to depict an eye disorder that is common in old age, the staff would be more likely to understand why this would be distressing for a client. Reading about the eye disorder is no doubt helpful, but experiencing it for yourself in an exercise is more useful.

The Grace Project training is provided in 32 hours of training. The Grace Project manual (2011) also provides a complete set of on-the-job (OJT) trainings for DSP staff to complete after they have received the Grace Project training. The format of the OJT's is identical to the OJT's required for the DSP's during their 80 hours of on-the-job training. The supervisor is to work through each OJT activity with the DSP and then sign off on the Core Competency Area Checklist when they have successfully completed the OJT. The Grace Project training would be provided in conjunction with the DSP training that is required by DHS, not in place of it. The staff that work with aging adults with ID need to be well equipped to serve them properly. Given the needs of an aging population, along with the needs of the ID population, it is unlikely that the DHS training for DSP's is sufficient to meet the higher and more specialized needs of the aging population. Some training departments may provide some extra instruction on specific populations they serve, but certainly not a 32 hour in-depth training on the aging process for aging adults with ID.

While no governing agency has set forth a mandate on staff to client ratios when serving aging adults with ID, it seems logical to assume that with the physical, social and behavioral challenges of aging that a smaller staff to client ratio would be prudent. The 1:5 ratio that is provided to adults with severe or profound deficits in adaptive behavior in the general day program setting would allow for better safety and individualized attention for the aging adult with ID.

A study by McCarron and Lawlor (2003) based out of Ireland examined how to best respond to the challenge of serving the aging and dementia population that also have intellectual disabilities. Specifically persons with dementia and ID require different personnel and a higher degree of health care and monitoring, as well as modifications to the environment (Janicki, McCallion & Dalton, 2002). People with ID who develop dementia continue to have special needs over and above those due to their dementia that can be best met by multidisciplinary ID staff that are trained and skilled in addressing such needs (Chicoine, McGuire & Rubin, 1999). McCarron and Lawlor (2003) recommend a regional ID dementia clinic that would provide diagnosis and assessment, multi-disciplinary assessment and clinical support, comprehensive person-centered services, advice on environmental modification and staff and family education and training. The areas of education and training are again stressed here because it is so vital to staff being able to properly support the changing needs of the aging population. While recognizing the difficulty of doing extra training in these areas due to limited time and resources, successfully supporting aging individuals with ID who do or don't have dementia depends on it. McCarron and Lawlor (2003) recommend providing training about normal aging and the diseases of aging, how to detect the early symptoms of dementia and how to best manage the cognitive and non-cognitive aspects of dementia in older people with ID. While there is not a

specialized clinic for people with ID and dementia in the Chicagoland area, it would be beneficial for individual agencies to apply the recommendations by McCarron and Lawler to help their aging population age in place.

Behavioral Interventions in Nursing Homes

A study by Allen-Burge, Stevens and Burgio (1999) showed that up to 80% of nursing home residents exhibit problem behaviors such as physical aggression, wandering, and repetitive vocalizations. Higher levels of behavioral and psychological symptoms of dementia have been found to be associated with more residents per room, lower resident function, lower staff levels and training, fewer activities and management that is less geared towards managing difficult behaviors (Brodaty, Draper, & Low, 2002). These problem behaviors can make providing them with care very difficult and problem behaviors are the most common precipitating factor for institutionalization (O'Donnell et al., 1992). Problem behaviors are also the most distressing for other patients. Pharmacological treatment of problem behaviors has been the most common course of treatment to address problem behaviors in nursing home residents (Kleijer et al., 2009). However, a study by Kleijer et al. (2009) showed that during treatment of nursing home residents with dementia with antipsychotic medication the severity of most of the behavioral problems continued to increase with only one out of six showing improvement. Due to psychotropic drugs having limited efficacy in the treatment of dementia related problem behavior, there is now consensus that patient care should not be limited to pharmacological treatment but also include non-pharmacological approaches (Deudon et al., 2009).

Prior to the emergence of behavior analysts in nursing homes, the social workers would have been responsible for trying to intervene when problem behaviors occurred. This would be an arduous task since social workers were not necessarily trained to assist with problem

behaviors. As such, they would likely just be reacting to behaviors that were already occurring as opposed to being proactive in an effort to prevent problem behaviors from occurring in the first place. Utilizing the expertise of behavior analysts to assist in addressing maladaptive or challenging behaviors with nursing home clients has shown to be effective.

According to Baker, Heinicke, and LeBlanc (2012), the same behavioral principles and procedures used with individuals with ID and autism have been proven effective with aging individuals with dementia. For example, functional analyses have been conducted and function-based treatments developed for individuals with dementia who had various topographies of problem behavior such as disruptive vocalizations (Buchanan & Fisher, 2002), wandering (Heard & Watson, 1999) aggression (Baker, Hanley, & Mathews, 2006; Dwyer-Moore & Dixon, 2007), and hoarding (Baker, LeBlanc, Raetz, & Hilton, 2011). Trained staff who know their patients can greatly reduce the levels of anxiety and behavioral issues that can develop during care and treatment (Tilly, 2008).

CNA's provide up to 90% of resident care in nursing homes, and therefore they need to be especially well-equipped to respond to these problem behaviors (Roth, Stevens, Burgio, & Burgio, 2002). The very nature of nursing home care requires that the CNA's be in frequent contact with the residents in order to provide assistance with personal care activities such as dressing, toileting, grooming and transferring. This is often the time that agitation occurs for residents. In a skill training study conducted by Burgio et al. (2002), nursing staff from two large nursing homes were trained to use behavior management techniques and communication skills while interacting with residents, along with a staff incentive system to facilitate the long-term use of the skills. Burgio et al. found that the staff training program resulted in a significant increase in the rate of positive statements made by CNA's and in a significant decrease in the

amount of time that agitated behaviors were displayed by residents during personal care interactions. This is further evidence that resorting to the use of psychotropic drugs to deal with problem behavior can be avoided frequently if the CNA's are given the proper training needed to respond appropriately when a problem behavior does occur, but more importantly how to interact in a way that will decrease the likelihood of the problem behavior occurring in the first place.

Behavioral Interventions in Programs With Adults With ID

Having behavior analysts on staff is an increasing trend in agencies that provide support to adults and children with ID. Prior to this trend, the clinical team at most agencies was made up of social workers and licensed therapists. While valid occupations in their own right, social work and general psychotherapy differ greatly from the practice of behavior analysis. DHS dictates that any person receiving ID services in an agency setting that is taking 2 or more psychotropic medications must have a behavior support plan to address the problem behavior that is causing them to need the psychotropic drugs.

According to DHS (www.dhs.state.il.us), a behavior support plan, sometimes called a behavior management plan, is a treatment and educational plan that is designed to provide guidelines for staff behavior to manage the individual's behavior and to teach alternative, appropriate behaviors in place of the problem behavior. Common components of a behavior support plan include target behaviors, functional assessment, data collection, intervention strategies, preventive measures, and replacement behavior training. There are many things to keep in mind when writing a behavior support plan. Some of these things include being as specific and concrete as possible, assigning responsibility for implementation, developing a checklist to correspond with each component, and developing scripts that specify responses for specific common behaviors.

There are also many obstacles to a successful behavior support plan, too many to include in the present discussion. Several are noteworthy, however, and cannot go without mention. The most prevalent is that the plans are not carried out in the way they were written. The staff that are likely going to be carrying out the plan are the ones that spend the most amount of time with the individuals, the DSP's. While they may have many years of experience with individuals with ID, that does not mean that they have many years of experience implementing functional behavior plans.

The DSP's need to be trained by the person that wrote the plan to ensure they have a clear understanding of the components and have demonstrated this to the plan author. Training a DSP on the plan is more than just having them read the plan and parrot back the words to you. It is also more than having just a general discussion about the problem behaviors. The plan author must train the staff so that they can competently perform the steps of the plan. The only way to show that they can do this is to demonstrate the skills in the plan.

While the DSP's are the staff that will most frequently be addressing problem behavior, other relevant staff also need to be trained on the behavior support plan so that they can assist whenever it is needed. This may include case management staff or program managers. The plan authors also have to be available to come and assist with crisis situations. They should also be observing the individuals on their caseload on a regular basis to determine if they need to make changes to their plan or if the staff need to be retrained on the skills of the plan.

Recommendations for Behavioral Interventions for Aging Adults with ID

Utilizing the expertise of behavior analysts or other people that are specially trained in problem behaviors is a must when working with aging adults with ID. As mentioned previously, many of the behavioral procedures and methods used to work with the general ID population

have been proven to work as well with the aging population. However, there are other things to keep in mind when providing behavioral support to aging individuals with ID. The increase in the life expectancy of all people, but specifically adults with ID, has increased the likelihood that they will live long enough to have some form of dementia. One factor that adds to this concern is the already high risk of dementia among some segments of the ID population (Janicki, Henderson, & Rubin, 2008).

The diagnosis of dementia in ID is an area where much future research is needed. Dementia screening in the general population is difficult and the baseline abilities in intellectual disabilities are so varied that only repeated measures over time are likely to result in an accurate assessment of dementia (Thorpe, Davidson, & Janicki, 2001). In a study by Janicki, Heller, Seltzer and Hogg (1996), it was suggested that behavioural measures should be repeated at set intervals after the age of 40 for individuals with Down Syndrome, and after age 50 in others with intellectual disabilities to detect functional changes, which can then be further evaluated clinically. The AAIDD website provides practice guidelines that give more details on assessment and care management in dementia (www.aamr.org). Dementia screening checklists are available to assist in tracking behavior if there is a concern that an individual is starting to show signs of dementia.

When an older adult with ID starts to display a new problem behavior, several things should be kept in mind. According to the Grace Manual (2011), there are four main categories that cause distress: fatigue, frustration, fear/confusion, and pain/discomfort. Staff need to be trained on the warning signs of dementia so that affective support strategies can be implemented to assist the individuals. Common behaviors that are associated with dementia include: shadowing, repetitive behavior, rummaging/hoarding, agitation, wandering, catastrophic

reactions, sundowning, delusions, hallucinations, suspiciousness, paranoia and pica (Clearbrook, 2011). A recent article by LeBlanc, Raetz, and Feliciano (2011) includes intervention methods for addressing many of these aforementioned behaviors. The way staff approach behavior problems with aging adults with ID that have dementia requires great patience and flexibility. Staff can better support the aging individual with ID and dementia if they keep in mind that dementia is a disease that affects the brain's ability to function and that their new, difficult behavior is not one within their own control. Common methods of treatment include educating staff, changing the environment, creation of a behavior support plan, distraction and medication.

Educating staff on the aging process (physical, social, emotional changes) and on the forms of dementia is the best way to equip them to do their jobs well. DSP's cannot make well-informed decisions if they are not trained on the individuals they are serving. Staff who are inadequately trained will become easily frustrated and lead to high staff turnover rates, which will further exacerbate the distress of the individuals they serve. Staff who are trained to understand and deal with the emotional needs and stresses of their individuals will be able to better provide an emotionally supportive environment that will minimize the occurrence of challenging behaviors or the perception of the person as a 'problem' (Thorpe, Davidson, & Janicki, 2001). Changing the environment is one of the simplest ways to make the programming area more comfortable and safe for the aging individuals with ID. Physical plant suggestions were discussed at length earlier in this paper. Creating a robust behavior support plan with the assistance of the interdisciplinary team should be a default response when providing support to an aging individual with ID, especially if they are displaying problem behavior. The Grace Manual (2011) stresses the importance of using distraction instead of arguing a point with an aging individual. This is especially true of an aging individual with ID and dementia. For

example, an individual you work with is insisting that they have to get ready to go to work, when in fact you know that they have not worked in many years. Reminding the person that they don't have a job may lead them to become upset or further confused. It may be more beneficial for you to distract them with another activity or provide them with a work activity that will occupy some of their time. Anti-anxiety or anti-depression medication is sometimes used in the early stages of dementia when a person is aware that something is wrong or changing with their mental faculties. There is no cure for dementia as this point in time, however.

Conclusion

The provision of quality services for aging adults with ID is an area of care that is becoming and will continue to become more necessary. As the life expectancy of the general population and the ID population continues to rise, special attention needs to be given to assure that these aging adults are provided with a positive quality of life in their aging years. The purpose of this paper was to look at: (a) the adjustments that need to be made to the environment/physical plant to foster the most independence and success in aging adults with ID, (b) models of care that will help promote healthy aging and a positive quality of life in the aging years, (c) training staff to address and support the needs of our aging population with ID, (d) addressing problem behavior in the aging ID population, and (e) the best model of care to use with aging adults with ID. Each of these five areas was reviewed by first noting current practices for typically developing aging populations in nursing homes, followed by practices for adults with intellectual disabilities. Finally, we provided suggestions for aging ID populations.

It is clear that much research is needed in the future to improve the standards of care for these individuals. The Grace Manual (2011) is a dynamic and forward-thinking training tool that can assist in equipping multiple levels of staff (DSP's, supervisors, management, etc.) to provide

quality services to aging adults with ID. A standardized and mandatory set of training in this area should be considered by DHS in order to better equip staff working with these individuals.

Future research should address how agencies that support individuals with ID can better prepare themselves to support their aging population, but also individuals that develop dementia. There are currently not vast resources for this group and many individuals that have ID and dementia are referred out of their agencies to either nursing homes or institutions because their agency doesn't have the structure in place to support their growing needs. Future research should address how to make training on how to provide support to older adults with ID a requirement for agencies and part of the general training protocol. Specialized training should be provided on top of that for people that are working with that specific population group.

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