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Clinical & Programmatic Considerations in Serving Aging Adults with Developmental Disabilities

Mary Jane Weiss, PhD, BCBA-D
Rachel Tait, MA, MEd

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Overview of Aging in the Developmentally Disabled

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https://www.bing.com/videos/search?q=aging+in+the+developmentally+disabled&&view=detail&mid=8D79F701ED240E12C2B88D79F701ED240E12C2B8&&FORM=VRDGAR

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Pre-aging considerations

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➢ Until they reach the age of 21, individuals with I/DD are eligible to receive support services (eg, education, training, health promotion) through the Individuals With Disabilities Education Act.
➢ When eligibility for these services ends, the task of securing support shifts from the educational system to the individual and his or her family or other caregivers.
➢ Funding cliff once students hit 21
➢ Significant shift in services post 21

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The aging transition

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➢ Current research provides no specific age range or cutoff that clearly defines the geriatric adult with I/DD.
➢ Typically, aging adults with I/DD may not have mobility or functional issues as observed in older adults in the general population.
➢ Adults with I/DD in their 40s may present with conditions commonly seen in the general population after the age of 70 (eg, diabetes, mental health deterioration, chronic respiratory conditions). Regularly scheduled physical exams play an important role in the monitoring and management of acute and chronic health conditions.
➢ This task of caring to individuals with a disability becomes more challenging over the individual's life span as aging-related changes impact both the person with I/DD and his or her supporting family members.
➢ Key challenges that must be addressed by communities, families, and adults aging with I/DD include improving the health and function of these adults and their families, enhancing consumer-directed and family-based care, and reducing barriers to health and community participation.

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Current Statistics

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➢ As a result of improved health care, individuals with intellectual and developmental disabilities (I/DD) are living longer than in past decades.

➢ Individuals with I/DD have experienced a more dramatic increase in lifespan than the population as a whole.

➢ The average life expectancy of people with I/DD was 22 years in 1931 but now approaches 70 for most people with I/DD and 60 for those with the most severe disabilities (Bigby, 2002; Bittles & Glasson, 2010).
➢ The rate of increase suggests that for most people with I/DD, life expectancy will approach that of the general population within a few decades.

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Statistics cont'd

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➢ The alarm has been sounding for some time now about the rapid aging of America's population and the capacity of our communities and service systems to handle the changes

➢ By 2030, the number of people over 65 is expected to reach 73 million, over 20% of our population. Compare this with 2010, when senior citizens made up just 13% of the population (Harvard Joint Center for Housing Studies (JCHS), 2014).

➢ While no specific census data exists on the number of older persons with I/DD, we can only rely on estimates.
  ○ There were an estimated 850,600 adults with I/DD age 60 and older in the US in 2012. Experts predict this number will reach nearly 1.4 million by 2030 when the last of the baby boom generation reaches age 60 (Factor, Heller, & Janicki, 2012).

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Federal and State Policy: Milestones on the Path to Inclusion

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- **1965: Medicaid** Title XIX, the Medicaid program, provides health-related coverage to low-income individuals and/or families and to people with disabilities.
- In 1972, Public Law 92-223 added Intermediate Care Facilities for Individuals with Developmental Disabilities to the Medicaid program.
- **1981: Home and Community-Based Services** The Omnibus Budget Reconciliation Act (OBRA) of 1981 amended Medicaid to allow home and community-based services (HCBS) under Section 1915(c) as an alternative to care in an institution.
  – These programs are known as "waivers," as CMS may waive certain requirements of the Medicaid program for states pursuing HCBS expansion
  – Home and community-based services may be offered at the option of a state and states may limit participation in these programs and establish waiting lists

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- **1990: Americans with Disabilities Act** The ADA prohibits discrimination and ensures equal opportunity for persons with disabilities in employment, state and local government services, public accommodations, commercial facilities, and transportation.
- **1999: Olmstead Decision** In Olmstead v. L.C., the court held that unjustified segregation of persons with disabilities constitutes discrimination in violation of Title II of the Americans with Disabilities Act
  – This landmark decision significantly increased access to home- and community-based services for people living in institutions, as well as those still in the community.
- **2000-2010: Funding Initiatives to Promote Community Living** In the decade following the Olmstead Decision, Congress authorized a variety of funding initiatives to compel states to reduce the institutional bias in long term supports and services (LTSS).

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- **2014: New HCBS Regulations** In January of 2014, the Centers for Medicare and Medicaid Services published final regulations implementing the new community options authorized under the Deficit Reduction Act of 2005.
  - The new regulations are an important step toward full community inclusion

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Aging in Place

- ➢ Aging in place, which has become a predominant theme shaping housing and other policies that relate to the needs of older adults in the United States.
- ➢ The Centers for Disease Control defines aging in place as "the ability to live in one's own home and community safely, independently, and comfortably, regardless of age, income, or ability level."
- ➢ Aging in place approaches, used in both aging and disability fields, allow individuals to continue living in the community setting of their choice and provide for any necessary assistance through a customized combination of formal and informal supports
- ➢ Aging in place is understood to encompass not only residential needs, but the full range of physical, functional, and psychosocial health concerns that contribute to successful aging for all people, with and without disabilities.

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Challenges

- ➢ As the baby boom generation ages and as lifespan continues to lengthen for people with I/DD, the capacity of state service systems to meet their needs is increasingly strained
- ➢ Lack of data on the exact numbers of older people with I/DD, their service needs, and the amount of unmet need creates planning and allocation difficulties for state agencies
- ➢ The challenges experienced by individuals aging with I/DD and those experienced by their caregivers.

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Medical Challenges with aging ●●eden ●●autism

➢ Adults with I/DD generally see primary care physicians less often in comparison with the general population. Several barriers contribute to this, including the following:
- ○ **lack of access** to primary care providers who are knowledgeable and experienced with the I/DD population;
- ○ **behavioral issues** that could negatively impact the individual's cooperation for tests, injections, etc;
- ○ **communication issues** that make interaction among the provider, caregiver, and patient difficult;
- ○ **physical challenges** (eg, cerebral palsy) that make it physically difficult to access a health care facility;

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- ○ **environmental issues** that may involve sensory challenges (eg, lighting, sound, smells) that interfere with a patient's ability to effectively participate in the visit;
- ○ **burn out** that renders caregivers unable to manage their own health in addition to the health of an adult with I/DD, including taking the adult to scheduled appointments; and
- ○ a **shortage of time** for providers to accommodate adults with I/DD who may have communication and behavioral difficulties that create challenges to patient assessment and treatment.

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Unique needs ●●eden ●●autism

➢ Certain conditions are strongly associated with aging adults with I/DD and are more prevalent among this population.
➢ There is a higher incidence of dental disease, functional decline, mental illness, bowel obstruction, gastrointestinal cancer, and obesity.
➢ Additionally, hearing impairment and vision loss are common in older adults with I/DD because of preexisting undiagnosed pathologies.
➢ Regularly scheduled screening and assessments (yearly or every six months, if required) is recommended along with a multidisciplinary approach to health maintenance.

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Key Health Issues

➤ Key health issues that require careful examination include the following:

- ○ **Pain and distress:** Nonverbal patients can be assessed with a caregiver's help as well as pain assessment tools adapted for adults with I/DD.
- ○ **Polypharmacy:** It's common for the I/DD population to have numerous medications prescribed by various providers. It's important to sort out medication use, capacity to follow the medication regime, and assistance required to support medication compliance.
- ○ **Vision and hearing:** Screen for cataracts and glaucoma (yearly for those aged 45 and older) and assess hearing, especially in light of reported changes in behavior. (Cerumen impaction may be a common cause.)

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- ○ **Dental disease:** General oral examinations may reveal the need for further investigation or closer monitoring by a dental professional.
- ○ **Musculoskeletal disorders:** Adults with I/DD are at high risk of osteoporosis and contractures related to reduced or limited activity. Osteoporosis occurs earlier in the I/DD population compared with the general population. Osteoarthritis also is an area of concern.
- ○ **Gastrointestinal disorders:** Screening plays an important role in the identification of gastroesophageal reflux disease. Colon cancer screening follows the same protocol used in the general population.
- ○ **Vaccinations:** Recent research reveals that adults with I/DD do not receive vaccinations at the same rate as adults in the general population.

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Special Consideration

➤ Adults with I/DD who also have mental health issues often are misdiagnosed. Psychiatric screening is imperative and tools such as the Abberant Behavior Checklist and the Psychiatric Assessment Schedule for Adults with I/DD are most helpful.

➤ Nonverbal patients pose a more complicated challenge, and it may be difficult to make a clear diagnosis when symptoms such as delusions and hallucinations are present.

- ○ Leading practice suggests the use of an interdisciplinary team of primary care providers, psychiatrists, and psychologists to manage psychological, emotional, and behavioral issues.

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➢ Most patients are accompanied to medical appointments either by a professional caregiver or a family member.
  ○ Although a caregiver's input can be helpful, clinicians are encouraged to not only include a patient in all interactions but also to speak directly to the patient unless communication becomes a barrier.
  ○ Even patients who have no verbal communication skills should be addressed by name during the visit and included in conversations pertaining to the routines and processes.
➢ Health goals for adults with I/DD are similar to those that apply to the general population:
  ○ to maintain or improve community participation, support a good quality of life (as defined by the individual and/or caregiver), promote wellness, and minimize acute care visits.

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Approach to Care

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➢ Careful planning prior to examining an adult with I/DD will ensure good use of scheduled time and no overlooked assessments.

➢ When planning for tests and screenings, there are important questions to consider, including the following:
  ○ What is the best way to communicate with this patient? This information can be obtained from someone who knows the patient well or directly from the caregiver.
  ○ Will the environment hinder the flow of the appointment (eg, distracting sounds, enclosed space, proximity to other patients)?
  ○ Are there sensory issues that may impede the appointment (eg, smells, light, white noise)?

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  ➢ Does the patient require sedation to complete any tests or exams?
  ➢ Can the caregiver assist with the visit (eg, repositioning the patient, answering questions)?
  ➢ Are any other health care team members needed to complete the visit, such as nurses, audiologists, speech therapists, or dietitians?
  ➢ Does the patient use adaptive devices (eg, iPad, communication cards, voice interpreters)?
➢ Clinicians can utilize care coordination to help monitor and manage the health of patients with I/DD. Care coordination does not need to be elaborate or increasingly time consuming.
➢ Because of the complex needs of this patient population, understanding and communicating with the patient's network of support ensures that all medical and social professionals involved with the patient are clear about the patient's health goals and strategies developed to accomplish those goals.

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Case study

- Other questions to consider
  - If Rita has behavioral issues, does she require any as-needed medications to help her relax prior to the appointment? Are there favorite toys or objects that can be brought to the appointment?
  - How much time should be scheduled for this appointment? Can Rita tolerate sitting or limited movement for this length of time?
  - Does Rita have sensory issues? Will they affect how the exam is conducted?

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The Appointment

- It was necessary to keep Rita's wait time to a minimum. For many adults with I/DD, sitting quietly in a waiting room for long periods of time may contribute to soreness, pain, or increased irritability.
- A friendly face goes a long way, so one staff member was assigned to assist Rita for the duration of her appointment, greeting Rita and her caregiver, providing reassurance and comfort, and preparing Rita for the new patient exam.

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- After being greeted and seated in the exam room, Rita and her caregiver could engage in familiar activities such as reading or playing with personal toys or objects.
- Once in the exam room, Rita spontaneously began self-stimulation ("stimming") by rocking back and forth and humming. Rita often does this when feeling anxious. The clinician waited until the stimming stopped. (An alternative would be to ask the caregiver to attempt to calm the patient or even redirect her attention to something else she enjoys.)
- Before beginning the exam, the clinician explained to Rita and her caregiver what would be done and confirmed with the caregiver what assistance would be needed. Short, direct face-to-face communication worked best with Rita.

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- Rita's tolerance dictated the exam's success. It was necessary for the clinician to monitor Rita's responses and modify procedures as necessary. For example, had Rita become agitated when the clinician attempted to assess her lungs, the caregiver and assigned staff member could have assisted with calming Rita while the clinician moved on to the next aspect of the exam. The overall goal is to make the experience a positive one for all involved.
- During the exam, it was necessary for the clinician to maintain periodic communication with both Rita and her caregiver. "Checking in" with a patient helps to establish trust and can help relieve anxiety. Checking in can be as simple as saying, "Rita, we're almost finished here. Are you OK? You're doing a fantastic job!"

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After the Appointment

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- Once the appointment was finished, the clinician reviewed his findings. With a collaborative approach in mind, he needed to decide whether other team members or clinical professionals could be instrumental in maintaining a good quality of life for Rita.
- The clinician had staff follow up with the caregiver by phone or e-mail to communicate the next steps for Rita's care and discuss subsequent appointments. He also asked for feedback regarding Rita's appointment, soliciting suggestions for improvement if there were any.

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Altering Treatment Goals to Reflect the needs of Aging Individuals

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How Goals may change

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➢ The goal is to assist individuals in maintaining their independence and support them in continuing to be active members of their communities.

➢ A person with a developmental disability, like anyone else, has the option of retirement from their life in the workforce. However, individuals with a developmental disability may not look forward to retirement.

➢ The reasons vary, but include economic loss, loss of socialization and friendships, isolation, and boredom. Each person's needs, interests, and fears are different

➢ Focus of programming will also need to change to accommodate an individuals changing needs and abilities

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What are the Activities of Daily Living (ADLs)?

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➢ The Activities of Daily Living are a series of basic activities performed by individuals on a daily basis necessary for independent living at home or in the community. There are many variations on the definition of the activities of daily living, but most organizations agree there are 5 basic categories.

○ **Personal hygiene** – bathing/showering, grooming, nail care, and oral care
○ **Dressing** - the ability to make appropriate clothing decisions and physically dress/undress oneself
○ **Eating** - the ability to feed oneself, though not necessarily the capability to prepare food
○ **Maintaining continence** - both the mental and physical capacity to use a restroom, including the ability to get on and off the toilet and cleaning oneself
○ **Transferring/Mobility**- moving oneself from seated to standing, getting in and out of bed, and the ability to walk independently from one location to another

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What are the Instrumental Activities of Daily Living (IADLs)?

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➢ Instrumental Activities of Daily Living are actions that are important to being able to live independently, but are not necessarily required activities on a daily basis. The instrumental activities are not as noticeable as the Activities of Daily Living when it comes to loss of functioning, but functional ability for IADLs is generally lost prior to ADLs. IADLs can help determine with greater detail the level of assistance required by an elderly or disabled person.

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The IADLs include:

➢ **Basic communication skills** - such as using a regular phone, mobile phone, email, or the Internet
➢ **Transportation** - either by driving oneself, arranging rides, or the ability to use public transportation
➢ **Meal preparation** - meal planning, cooking, clean up, storage, and the ability to safely use kitchen equipment and utensils
➢ **Shopping** - the ability to make appropriate food and clothing purchase decisions
➢ **Housework** - doing laundry, washing dishes, dusting, vacuuming, and maintaining a hygienic place of residence
➢ **Managing medications** - taking accurate dosages at the appropriate times, managing re-fills, and avoiding conflicts
➢ **Managing personal finances** - operating within a budget, writing checks, paying bills, and avoiding scams

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Retirement planning

- ➢ Planning should be done in advance of actual retirement
- ➢ Staff should conduct individualized assessments and develop transition plans.

- ➢ Transition plans are driven by the wants and needs of the individual, with input from family members and others who know the person well.

- ➢ Each retirement plan should be custom designed and may also include supports for family members

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What retirement planning could look like

- Change in focus from employment to volunteer activities
- Heavier focus on ADL's
- Development of recreation and leisure activities
- Social activities with peers
- Community integration

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Changing up the day

- Reassess activity schedule
- Simplify activities
- Establish new activities or routines *
- Separate space that is quieter or with better lighting
- More frequent bathroom breaks
- Start the day later, go at a slower pace
- May need to introduce OT or PT
- Access interagency aging program activities

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Person Centered Planning

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- ➢ Person-centered planning (PCP) is now almost universally understood as a necessary component of an effective delivery system for long-term services and supports (LTSS)

- ➢ When done well, person-centered planning can ensure greater independence and a better quality of life for seniors and people with disabilities receiving LTSS

- ➢ All too often, LTSS consumers receive barebones or one-size-fits-all service plans driven exclusively by functional needs assessments, a danger that is potentially greater when LTSS are delivered through managed care systems (Orlowski & Carter, 2015)

- ➢ The focus of PCP planning should be the goals, wants, needs, and strengths of the individual.

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NADD — Person Centered Planning

NON-NEGOTIABLES
items that a person cannot live without to maintain their health and safety within a community setting.

STRONG PREFERENCES
Such things as music, sports, parties, crafts, movies, and church activities may be listed here.

HIGHLY DESIRABLES
These are the hopes and dreams of the individual. Anything from a vacation in Hawaii to a new winter coat may be listed here depending on the individual's immediate needs and dreams for the future.

WHAT DO YOU NEED TO KNOW?
Issues as eating habits, personal care, and safety issues may be covered here. There may be certain things that upset an individual such as loud noises. These are listed here also.

SUPPORTS/BARRIERS
An example for an individual who is fearful of or cannot negotiate stairs, a one-floor home is recommended. This area may also include financial supports, behavioral supports, therapeutic supports, and medical supports if needed.

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What is an enabling/ person centred approach?

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1. Promotes active ageing and social inclusion

2. Promoting independence, by restoring capacity and well-being through activity, social connections, skills and assistance

3. Focuses on a person's goals and tailors support to individuals. This includes what is important for and important to a person

4. Builds on a person's strengths and interests and their life story

5. Builds positive partnerships

11 September 2014

Enabling Independence and Person Centred Approaches ©t Carrie Hayter Consulting

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Activity

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Use the information provided to fill this profile

One page profile

Me
Me

What people like and admire about me...
What people like and admire about me

History
History

Hopes and dreams for the next few months
Hopes and dreams for the next few months

What's important to me...
What's important to me

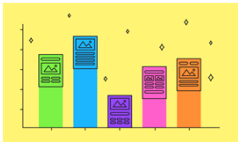How best to support me...
How best to support me

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OUTCOME MEASURES AND DATA COLLECTION

How does it change?

How do we collect data before aging?

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- In childhood
  - Acquisition of skills
  - Behavioral disruption
  - Behavioral regulation
    - FCT responses

DATA in adulthood

Collect data on:
  » Generalization of skills
  » Social behaviors (initiations, responses)
  » Behavioral data/DISRUPTION
  » Engagement/CONNECTION
  » Conversation
  » INDEPENDENCE (prompts)
  » Other qualitative elements (speed, thoroughness)

What needs to shift?

- More relevant
  - Choice
  - Leisure
  - Independence
  - Safety
  - Health indicators and preservers
- Less relevant
  - Work engagement
  - Traditional productivity measures

leisure opportunities

CHOICE

- Provision of choices in a natural progression in adult lives
- Choices are maximized (hopefully) with aging)
- More control over schedule is normative with aging

LEISURE

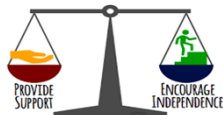- As work becomes less relevant, leisure becomes more prominent

INDEPENDENCE

- What does this mean?

SAFETY

- Concerns increase with aging
- Specific risks
  - May be more vulnerable to falls
  - Medical problems may increase risk
  - Forgetfulness might impact
  - Disorientation may be a concern for navigation or for other reasons

HEALTH INDICATORS AND PRESERVERS

- Number of falls
- Number of trips to nurses
- Ability to exercise with regularity
  - Participation in movement groups
  - Walking
  - Community outings
  - Are there kinds of activities that match individual?
    - Swimming
    - Seated stretching

OUTCOME MEASURES

- Should include happiness

QUALITY OF LIFE AND HAPPINESS

- What do we know about these elements of programming?
- Are we assessing them as outcomes?

What are components?

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- – DIMENSIONS
  - physical health
  - psychological state
  - level of independence
  - social relationships
  - personal beliefs
  - relationship to the environment

Happiness- operationally defined

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- Happiness = Private Event
  - – Self-Report
  - – Indices
    - Overt behaviors
    - Observable

- Green, Gardner, & Reid, 1997; Green & Reid, 1996; Green & Reid, 1999; Green & Reid, 2005; Parsons, Reid, and Lattimore, 2012

Evaluate happiness

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- Evaluate activities designed to promote happiness
- Identify unhappiness during events
  - – Alter events?
  - – Prevent distress?

Our goal…………

- Our goal in targeting skills should be to create changes that
  - Are socially significant
  - Are meaningful
  - Occur in natural environmen
  - Occur in generalized contex
  - Occur spontaneously
  - Lead to a better quality of lif

CREATE MEANING

Another index of change: Social validity

- Are the changes making a meaningful difference in this person's life and in the lives of those he or she encounters?
  - More rewarding interactions
  - Fewer negative interactions
  - More independence
  - Fewer assists from caregivers
  - Positive reactions from other community members
  - Increased openness and real community integration
  - Happiness
  - Choice

Should include organizational measures

- Individualization of care plans
- Involving the individual in creating their care plan
- Level of engagement
- Measures of choice provision
- Safety
  - Falls
  - Medication errors
  - Monitoring of main medical conditions with consistency

Think of one individual

- Come up with 5 ways to collect data
- Focus on
  - Choice
  - Leisure
  - Independence
  - Safety
  - Health

Retirement
NEXT EXIT

Think of organizational metrics

- Come up with 3 indicators of success
- HOW WOULD THESE PROVE YOU ARE MAKING PROGRESS IN THESE AREAS
- Focus on
  - Safety
  - Choice
  - Including individual in care plan

ACHIEVEMENT

Ethics in the context of service provision for aging adults with ASD

Ethical and humane treatment

- Context of history
- Broad ethical mandates
- Seminal articles
- Recent updates
- Meta-changes in views

Egregious violations of human rights

- Historically, individuals with disabilities have been subjected to
  - Lack of effective treatment
  - Inhumane conditions
  - Violations of basic rights
  - Experimentation without consent
  - Lack of choice
  - Lack of control
  - Severe punishment and coercion
  - Absence of skill acquisition programming

Egregious violations of human rights

- Examples – exposed atrocities
  - Sunland in Florida 1970's
  - Willowbrook NY in 1960's and 1970's (6,000 people with IDD)
    - Inhumane
    - Lack of care
    - Lack of privacy
    - Warehousing

What are the broad ethical mandates that govern our professional care?

- APA
- **Principle A: Beneficence and Nonmaleficence**
- **Principle B: Fidelity and Responsibility**
- **Principle C: Integrity**
- **Principle D: Justice**
- **Principle E: Respect for People's Rights and Dignity**

Specific points under Rights and Dignity

- Respect the dignity and worth of all people
- Privacy
- Confidentiality
- Self-determination
- Safeguards for the most vulnerable

From the Professional and Ethical Code for Behavior Analysts

- Boundaries of Competence.
  - All behavior analysts provide services, teach, and conduct research only within the boundaries of their competence, defined as being commensurate with their education, training, and supervised experience.
  - Behavior analysts provide services, teach, or conduct research in new areas (e.g., populations, techniques, behaviors) only after first undertaking appropriate study, training, supervision, and/or consultation from persons who are competent in those areas.

Overarching Obligation: Best interests

- Behavior analysts have a responsibility to operate in the best interest of clients.

Bio-behavioral interface

- Medical Consultation.
- Behavior analysts recommend seeking a medical consultation if there is any reasonable possibility that a referred behavior is influenced by medical or biological variables.

Involving the Client

- Explaining Assessment Results.
- Behavior analysts explain assessment results using language and graphic displays of data that are reasonably understandable to the client.

Involvement and Individualization

- Involving Clients in Planning and Consent.
  - Behavior analysts involve the client in the planning of and consent for behavior-change programs.
- Individualized Behavior-Change Programs.
  - Behavior analysts must tailor behavior-change programs to the unique behaviors, environmental variables, assessment results, and goals of each client.

From the Treatment Section

- Describing Conditions for Behavior-Change Program Success.
  - Behavior analysts describe to the client the environmental conditions that are necessary for the behavior-change program to be effective.
- Considerations Regarding Punishment Procedures.
  - Behavior analysts recommend reinforcement rather than punishment whenever possible.
- Avoiding Harmful Reinforcers.
  - Behavior analysts minimize the use of items as potential reinforcers that may be harmful to the health and development of the client, or that may require excessive motivating operations to be effective.

Promoting an Ethical Culture

- Behavior analysts promote an ethical culture in their work environments

What are the implications?

- Strong foundation of ensuring humane treatment that ensures dignity is protected
- Recognition that organizations must endeavor to train staff and create a climate conducive to humane care

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Ethical safeguards and entitlements

- What are some of these safeguards?
  - Exposure of atrocities
  - Explicit commitment to humane care
  - Review levels internally and externally
  - Position statements
  - Professional articles
  - Regulatory agencies and their reviews

Seminal article: The right to effective behavioral treatment

- Van Houten et al (1988)
- Individuals who are recipients of services have rights regarding treatment.
- Behavior analysts have an obligation to make available the most effective treatment that the discipline can provide.

Clients' Rights

- ◆ 1. The right to a therapeutic environment
- ◆ 2. The right to services whose overriding goal is personal welfare
- ◆ 3. The right to treatment by a competent behavior analyst

Clients' Rights

- ◆ 4. The right to programs that teach functional skills
- ◆ 5. The right to behavioral assessment and ongoing evaluation
- ◆ 6. The right to the most effective procedures available

The Right to a Therapeutic Environment

- ◆ A physical and social environment that is
  - – safe
  - – humane
  - – responsive to individual needs

A Therapeutic Environment includes……..

♦ Access to therapeutic services, leisure activities and materials that are enjoyable (as well as instructive)
♦ Client preference is considered in selection of materials and activities
♦ Frequent, positive interactions
♦ An absolute minimum of restrictions
  – freedom of movement
  – access to preferred activities

The Right to Services whose overriding goal is personal welfare

♦ Focus on maximizing independence
♦ Including the person in treatment decisions
♦ Peer Review Committees
  – experts use professional standards to determine clinical propriety of treatment programs
♦ Human Rights Committees
  – impose community standards to determine propriety of treatment programs
  – comprised of consumers, advocates, other interested citizens

Human Rights Committees

• examine compromises to individual's
  – dignity, privacy, and access to humane care
  – appropriate education and training
  – prompt medical treatment
  – access to personal possessions
  – access to social interaction and physical exercise
  – access to humane discipline
  – access to physical examinations (prior to plan)

The Right to Treatment by a Competent Behavior Analyst

♦ Professionals delivering, directing, or evaluating the effects of behavioral treatment must have appropriate education and experience.
♦ Education includes:
  – knowledge of behavioral principles
  – methods of assessment and treatment
  – research methodology
  – professional ethics

The Right to Treatment by a Competent Behavior Analyst

♦ Clinical competence includes
  – adequate practicum training and supervision
  – experience with the population

Access to doctoral level behavior analysts

♦ Access should be available when case is complex or poses risk
♦ This individual can conduct a comprehensive functional assessment
♦ This person can also provide training in the methods of intervention, and follow up training and consultation as needed

The Right to Programs that Teach Functional Skills

- ♦ Focus on the acquisition, maintenance, and generalization of behaviors that allow the individual to gain wider access to preferred materials, activities, or social interaction.
- ♦ Focus also on behaviors that allow the individual to terminate or reduce unpleasant sources of stimulation
- ♦ Focus on behaviors that prevent independence and interfere with these goals

More on Functionality

- ♦ A right to services that will assist in the development of behavior beneficial to society
- ♦ A right to participation in and access to all aspects of community life

Are programs functional?

- ♦ What is functionality?
- ♦ What determines functionality of a program?
- ♦ How can we help educators develop more functional programs?

What is functionality in the context of aging?

- Work?
- Leisure?
- Naps?
- Maintaining independence vs. offering support

The Right to Behavioral Assessment and Ongoing Evaluation

- A complete functional assessment
  - Examining antecedent events as well as consequent events
  - Begins with examining when behavior occurs and a variety of other contextual variables
  - Includes direct observation of the individual's behavior
  - Objective data are evaluated in an ongoing manner

Behavior analysts…..

- Maintain accountability
- Solicit input
- Share data with all concerned parties regularly

2/2

The Right to the Most Effective Treatment Procedures Available

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♦ Refers to effective and scientifically validated treatment
♦ Restrictive procedures are used only when they are necessary to produce safe and clinically significant behavior change

The Right to the Most Effective Treatment Procedures Available

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• At times a restrictive procedure is considered, if a nonrestrictive procedure…….
  – Increases risk
  – Inhibits or prevents participation in a needed training program
  – Delays entry into a more optimal environment

Level of restrictiveness

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♦ Is a complex issue
  – Absolute level of restrictiveness
  – Amount of time required to produce clinically acceptable outcome
  – Consequences associated with delayed intervention

The Right to Personal Liberties

- Bannerman, Sheldon, Sherman, & Harchik, 1990
- People should have a variety of available options, and should be free to choose from among them
- "Uncoerced" choices: there are no implicit or explicit consequences for selecting one alternative over the others (except for the characteristics of the alternatives themselves)

Things people decide........

- when to take a shower
- what to eat, when to eat
- with whom to spend time
- whether to take a day off from work
- whether to take a nap
- what to watch on tv

Things older adults decide

- How to alter their work schedule
- When to retire
- Where to live in retirement
- What leisure pursuits to engage in

Are we compromising liberties to achieve habilitation?

- ♦ 1. Clients may have little input regarding treatment goals or instructional methods
- ♦ 2. Behaviors may be taught without regard to preferences or past learning in the area
- ♦ 3. Choice making is often not taught
- ♦ 4. Opportunities for choice are limited

Some implications

- ♦ Preferences of clients should be assessed
- ♦ Client input should be considered in the selection of goals, methods, materials, etc.
- ♦ Choice-making skills should be taught
- ♦ Choice-making should be available both within and between scheduled activities
- ♦ Creativity and flexibility are needed to determine how to honor choices

Other issues

- • Withholding goods and services
- • Ways to behave and speak to adults with disabilities

Dignity (from Reid, Rosswurm, & Rotholz, 2017)

- "the quality or state of being worthy, honored, or esteemed" (Merriam-Webster's Collegiate Dictionary, 1971
- "the idea that a being has an innate right to be valued, respected, and to receive ethical treatment"

Can we operationally define dignity?

- What do you think of?
- What is respectful?
- How does it get manifested in words?
- How does it get manifested in actions?

Ways to speak to adults with disabilities

- Table 1 Speaking About Adults With Disabilities in Ways That Reflect Dignity in Specific Situations
- Recommendations
- Refrain from speaking about a person with a disability in the immediate presence of the individual without involving the person in the communication; attempt to speak about the person to another individual in a separate location or at least in a manner that is not likely to be apparent to the person who is the focus of the conversation.
- Refer to the person, not a behavioral characteristic.
- Avoid the potentially pejorative term low functioning; consider people-first language, such as someone with "more significant" or "more severe" disabilities.
- Respect the adult status of the person.

Ways to behave toward people with disabilities

- Table 2 Behaving in Ways That Reflect Dignity
- Recommendations
- When escorting or traveling with an adult with a disability Walk side by side with the person, not in front of the person.
- Whenever possible, push a wheelchair from the side instead of from behind.
- If it is necessary to physically prompt movement, do so from the side by guiding the elbow or with a hand lightly on the lower back in contrast to pulling or tugging the person.
- If you are traveling with a group of adults with disabilities in a van or similar vehicle, sit with the people with disabilities in contrast to segregating them in the back of the vehicle from support persons who sit in the front.

More ways to behave

- Sit with a group of individuals in public places (e.g., restaurants) in contrast to support persons sitting at one location and the people with disabilities being segregated at another sitting location.
- Refrain from eating or drinking in the presence of individuals with disabilities when they do not have opportunities to eat or drink; either restrict eating and drinking to situations in which the people with disabilities are not present or ensure that everyone present has immediate opportunities to eat or drink.
- Support a dignified appearance: When an individual's grooming or attire may place the individual in an undignified or otherwise negative light, take immediate action to remedy his or her appearance.

Final quote from Reid et al

- "In short, treat others as you desire to be treated. This principle of human reciprocity is well accepted across numerous cultures ("Golden Rule," n.d.). Relatedly, when considering how to speak or behave in regard to an adult with IDD, behavior analysts can decide if they would want their son or daughter, mom or dad, grandmother or grandfather, or any other loved one treated in a certain way. If not, then behavior analysts should generally refrain from treating people with IDD in that manner. "

What does dignity mean for those who both have a disability and are aging?

- Other layers/questions
- What are other indignities for the aging?
  - Infantilization
  - Failure to acknowledge their presence
  - Speaking around them or to caregivers
  - Reducing their voice in treatment
  - Failing to maximize their independence in safe ways

Normal goods and services

♦ What should be considered normal goods and services?

Scenarios

Summary

- What are the meta messages
- PROTECT DIGNITY OF THOSE WE SERVE
- CREATE AN ETHICAL CULTURE
  - Tools
  - Awareness
  - Drift Patrol
  - Outside oversight

Logistics Around Staffing Considerations and Training

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Staffing items

- Development smaller groups with higher staff ratios
- Additional support staff
  - Speech, clinical, nursing, OT,PT, dietician, social workers, etc
- Ratios increase
  - May require more 1:1 with physical and medical issues

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Training

- Training specific to needs of aging population
  - Programmatic focus change
    - Rec & leisure, community integration, volunteer
  - Implementation of ADL's
  - Schedule changes
- Training specific to dementia
- Training in specific medical orders
- Training on changes around aging

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Training cont'd

- Understanding of adaptions needed for program space
  - How to use the space, ensure safety, etc
- Training should extends beyond physical care, safety, and resident/client rights to include training in resident/client choice, independence, and inclusion

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End of life

- Staff working with people with IDD need education to understand dying, death and end-of-life planning
- They can be better prepared to support family members and the individuals with IDD to assure that the full range of choices and care options are available in this phase of life.
- These conversations should take place well before these items become a concern in the participants life

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Program to Program

- Open communication from residence to day program
- Make sure all unusual incidents or concerns are shared
- Make sure all medical orders are transferred and kept up to date

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Tapping into resources

- ➢ A collaborative approach has proven to be the most successful in the care of adults with I/DD.
- ➢ Clinicians and staff can rely on several resources to develop a plan of care for I/DD patients.
- ➢ Caregivers provide a good source of personal and practical information, and community support agencies such as the Developmental Disabilities Services and the Administration on Intellectual and Developmental Disabilities (at the federal level) that connect patients with community resources and funding are an instrumental part of the care continuum.
- ➢ Accessing information from community resources may be necessary to get a better understanding of a patient's level of function in the community in order to set realistic health goals.
- ➢ The patient and/or a caregiver will be able to provide background information regarding which specific local community agencies provide him or her with financial and social support

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Environmental Modifications to Promote Safety

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The right to age in place

- No matter when the older person's home was built and regardless of whether it is modern or traditional in style, it likely was designed for young adults and their young families

- As adults age their homes also grow older, but most are not updated to accommodate a senior's changing needs

- Home adaptation or modification can provide friendlier elder living so older occupants may continue to live safely in their own home.

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What is Aging in Place?

- Aging in place is a term used to describe a person living in the residence of their choice, for as long as they are able, as they age. This includes being able to have any services (or other support) they might need over time as their needs change.

- The act of aging in place, takes place during a period of time in an elderly person's life where they can have the things that they need in their daily life, while maintaining their quality of life.

- The goal of an elderly person (or anyone) wanting to age in place should be to maintain and/or improve their quality of life.

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Areas to Focus on

- The focus in making a home elder-friendly should always be on increasing and improving the following five elements:
  - Self-sufficiency/self-reliance
  - Mobility
  - Safety
  - Security
  - Comfort/convenience

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Deciding How and When to Undertake Home Modification

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➢ The best time to start thinking about home modification is long before the need actually arises.

➢ Ideally, we should be preparing ahead, when our participants are in their 40's and 50's and prepare their homes for later installations while doing routine home improvements and repair

➢ Extra wide doorways that can accommodate a wheelchair can be an attractive feature in any home.

➢ Strong supports can be installed behind tile walls when updating bathrooms to later accommodate grab bars

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Home modification

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➢ It's likely not possible to make any home completely accident-proof and so that should not be the main goal of home modification.
➢ Where possible, emphasis should be placed on preserving and strengthening the capabilities of the older person
➢ It would be contrary to the goal of enhancing independence to force unwelcome changes on a reluctant older person.
➢ The exception, of course, would be someone suffering from dementia who is unable to meaningfully participate in such decision making.

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Home Modification

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➢ It is always best to undertake home modification before a crisis occurs so that the work can be carefully planned and budgeted.

➢ Before any changes in the home environment are considered, a thorough room-by-room assessment of the surroundings should be made.

➢ This should include consideration of the resident's current and future needs, the way in which he/she uses the home and its contents and any barriers that might limit movement or access.

➢ A good general safety checklist that can be used for this purpose is available without cost from the U.S. Consumer Product Safety Commission (CPSC) in Washington D.C.

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Advanced Home Modifications

- Some home modifications are more involved and you can make your home safer and more comfortable for years to come.
- **Install grab bars.**
  - As keeping balance becomes more difficult, having grab bars in various spots around a home can be the difference between catching themselves or falling down.
  - In the bathroom, the hallway, and next to the bed are all smart spots to add grab bars.
- **Widen your doorways.**
  - If mobility issues reach the point where a wheelchair, a walker, or even just crutches, are needed, have more space to get through your doorways will be a blessing

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Cont'd

- **Add a stair lift**
  - Stair lifts are costly, but if there are stairs in a home and the participants can no longer walk up and down them safely, then it's an important addition to your home.
  - Some forms of insurance may help cover the cost of stair lifts, so if one is needed one but find the cost prohibitive, it's worth doing some research to see if part of the cost will be covered
- **Install a walk-in tub**
  - Getting in and out of the tub is one of the most difficult and risky tasks a senior faces once they start to have mobility and balance issues.
  - Like a stair lift, a walk-in tub is a pretty costly addition to your home, but one that can increase the ease and safety of bathing considerably.

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Cont'd

- **Install wheelchair ramps.**
  - Finally, any senior that starts to need a wheelchair to get around will need wheelchair ramps installed in various places around the home.
  - Wheelchair ramps won't become necessary for all seniors, but for those that do need them they'll make all the difference in being able to stay in their own home.

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- https://www.youtube.com/watch?v=wBSy7Vr GOVU

- https://www.youtube.com/watch?v=fLginqA_ Cgg

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Universal Design

➢ With the population aging, universal design has become a hot topic. Seniors want to stay in their homes and age in place rather than be segregated in older adult communities or assisted living communities.

➢ Sometimes called "Better Living Design" or "Aging in Place" design, a Universal Design approach melds a safe, practical and accessible conveniences with a modern and updated aesthetic.

➢ Improved efficiency and ease in navigating and using the space for the people who live there, or who visit often.

➢ Clients may look at incorporating Universal Designs into their home if they'd simply like to make it safer and easier to live in their home for as long as possible, or if special needs are assessed and required.

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Activity

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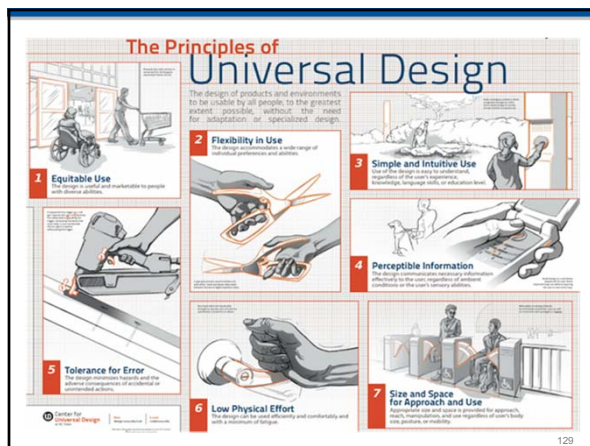
On the next slide, identify all the modifications that have been made to make the bathroom more accessible

130

131
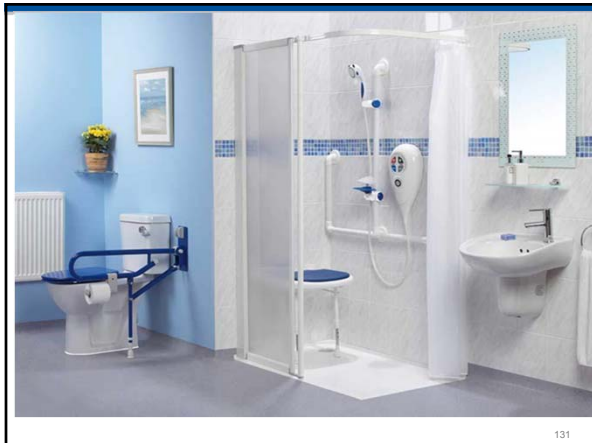
Activity

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➢ Working with the person next to you; think about your current workplace or group home. What changes would you need to make in order to utilize universal design in that environment?

132

BEFORE — Presence of kerb at door entrance

AFTER — Installation of removable wooden ramp with non-skid covering

133
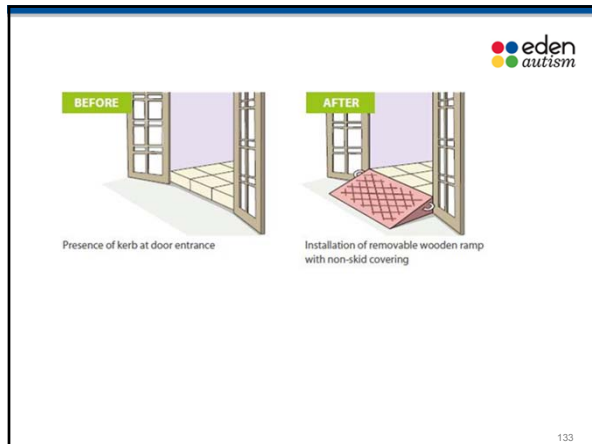
Day Center Modifications

- Modifications similar to those in residence (rails, clutter/physical layout, lighting)
- Reduce noise (quiet room/breaks room)
- Visual cues (clearly identify bathrooms, kitchen, etc.)
- Use safety monitoring – door alarms, etc (when necessary)
- Other safety measures may include smaller groups and more support staff

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Supports to Enhance Orientation & Engagement

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Defining Active Engagement ●● eden
●● autism

Active Engagement refers to the level of interaction with a learning environment, including other individuals, activities or an item.

●● eden
●● autism

Look at the following pictures and share if you think the picture resembles a situation where active engagement is taking place. Why or why not?
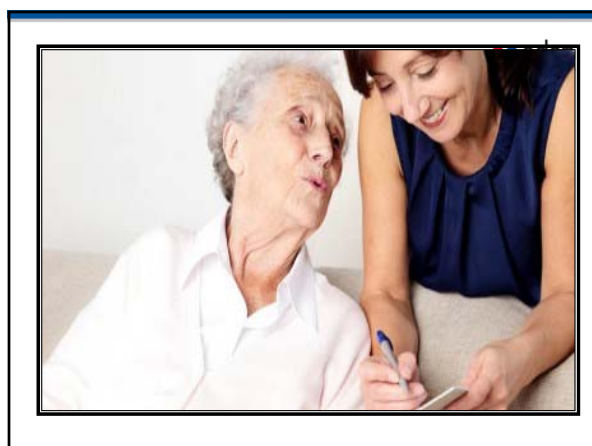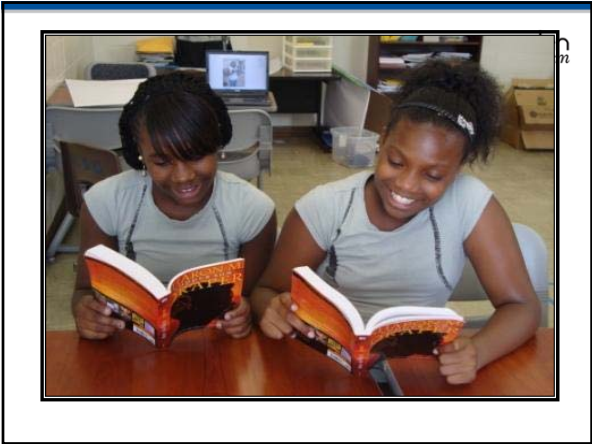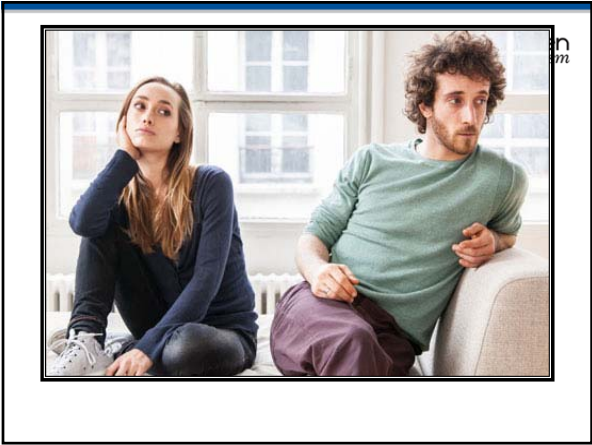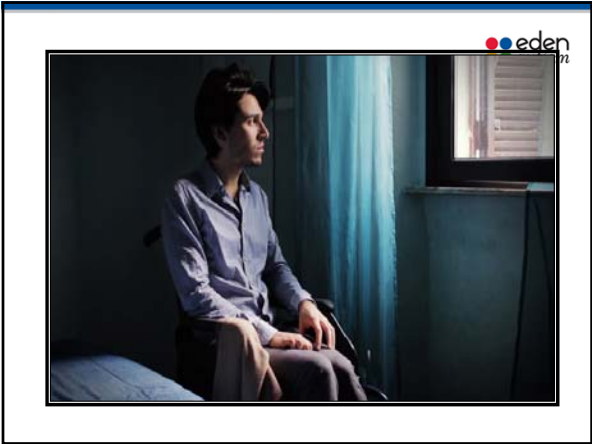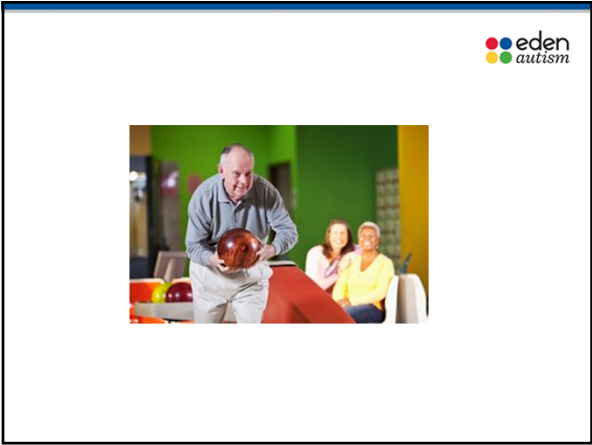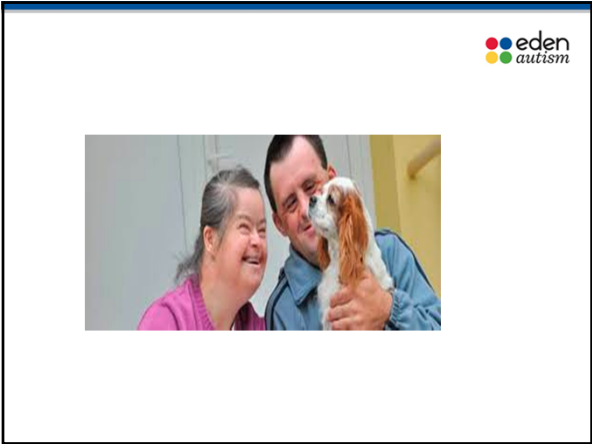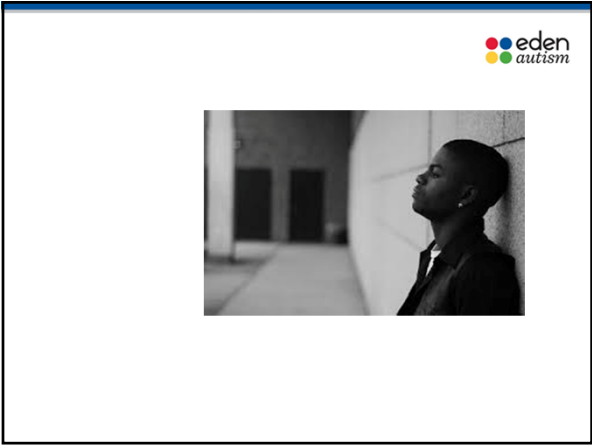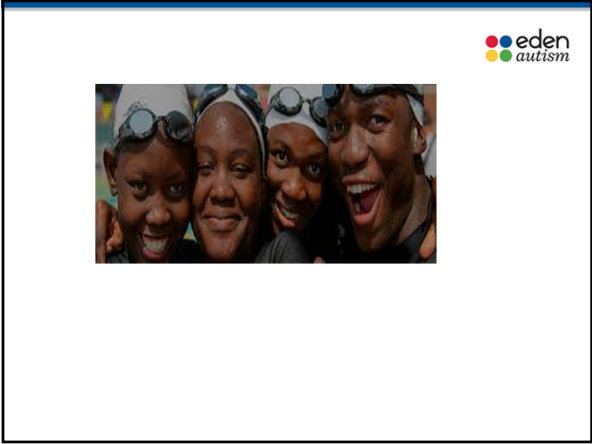
WHAT SHOULD WE SEE?

- HAPPY AFFECT or MOOD
- INTERACTION- person to person
- PHYCIAL PROXIMITY
- EYE CONTACT
- PROVISION OF ACTIVITIES
- SHARED ACTIVITIES
- SHARED ENJOYMENT

GOALS

have lots
of fun.

Enrichment
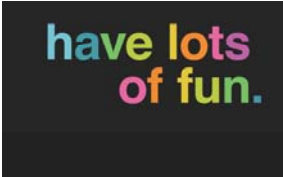
Give examples of how you
use active engagement when
working with our individuals

Safety vs. Active Engagement

An employee is able to maintain appropriate safety by
being in close proximity (distance, being near a person) or
visual sight. While keeping an individual safe is vital,
merely maintaining proximity does not encourage or
demonstrate active engagement.

HOW IS IT
DIFFERENT?

WHAT MAKES IT ENGAGEMENT?

Active Engagement & Direct Care

o HOW IS IT DEMONSTRATED
o Interaction
o Encouraging communication
o Improving social skills
o Providing differential reinforcement

BE PRESENT

Encouraging Communication

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Encouraging Communication: What can <u>YOU</u> do?

- Build rapport with individuals; PAIR
- Talk with clients
- OBSERVE
- LEARN about and respect their likes and dislikes
- Respect privacy and boundaries
- Demonstrate respectful and polite behavior
- Model appropriate communication
- REINFORCE!!

Modeling Appropriate Communication

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- ❑ Say "please" and "thank you"
- ❑ Use a respectful tone
- ❑ Avoid intimidating body posture
- ❑ Avoid talking about the individual
- ❑ Avoid side/private conversations
- ❑ Be aware of facial expressions
- ❑ Do not talk down to the individual
- ❑ Do not nag or give "orders"
- ❑ Do not interrupt the individual
- ❑ Demonstrate listening skills
- ❑ Be careful of sarcasm and humor

Follow these rules whether or not the client is able to engage in vocal conversation

How can we encourage communication for individuals who are non-vocal?

What challenges do you face engaging with individuals who are non-vocal?

Common Mistakes When Working with Non-Verbal Individuals

- Talking about the individual as if they were not present
- Making choices for the individual
- Offer choices
- Encourage decision making
- Provide opportunity for non-vocal responses
- Learn preferences!
- Not providing verbal attention or reinforcement or praise
- Be sure to make eye contact or be at eye level
- Use positive facial expressions (SMILE)
- Use upbeat, calm, friendly and positive tones
- Use an appropriate volume
- Avoid shouting or loud levels of speaking
- Remember: It is not just WHAT you say but HOW you say it

Keep Talking

- Interact with all clients - What Can You SAY?
- Provide reinforcement
- "Great job using your napkin!"
- Ask questions about their day
- Provide compliments
- "I love that color shirt you have on today!"
- Make general statements
- "It is so hot out there today, I wonder what the weather will be tomorrow"

The Talking Challenge! eden autism

Pair up! Assign one person the role of a client and the other the role of the staff member. The client is non-vocal. Come up with an activity for the client to be engaging in (writing, matching task, eating...). The staff member must talk with the person for one minute without any vocal response from the client.

TIME FOR ACTION

Using Reinforcement eden autism

Motivation & Reinforcement eden autism

Reinforce appropriate communication!
- ❖ **Asking for help**
- ❖ **Saying "please" or "thank you"**
- ❖ **Requesting an item/activity**
- ❖ **Engaging in reciprocal conversation**
- ❖ **Social interaction with peers**

Together WE Achieve More

Remember: **Reinforcement increases the likelihood of the behavior happening again in the future**

Delivery of Reinforcement

Delivery should be:
- ✓ Immediate
- ✓ Distinct
- ✓ Varied
- ✓ Specific
- ✓ Consistent
- ✓ Meaningful to the Individual

Avoid the "Good Job" Trap!

GOOD JOB GOOD JOB GOOD JOB
GOOD JOB GOOD JOB
GOOD JOB GOOD JOB GOOD JOB

Activity!
Come up with as many different ways to provide verbal praise as you can in 30 seconds!

Enhancing Social Skills

- ✓
- ✓
- ✓
- ✓
- ✓

Reciprocal Play/Leisure

Parallel play/leisure involves individuals engaging in an activity mostly on their own. Multiple people may be engaging in the same activity, but do not interact.

Reciprocal Play/Leisure involves individuals interacting with others as they engage in an activity.

Example: Reading a Magazine

Parallel Play/Leisure: An individual and staff member looking a separate magazines independently.

Reciprocal Play/Leisure: An individual and staff member looking at the same magazine and commenting on pictures, colors, asking questions, or reading the magazine out loud.

Group Activities

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o What are group activities you arrange in your day program environment or residential home?
o What are the challenges of arranging a group activity?
o What are the benefits of group activates?
o What are times of day group activities easy to arrange?
o What are times of day when group activates are difficult to arrange?
o What do you do if an individual refuses the activity or is not interested?

Group Activity Basics

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o Get everyone in the group involved!
  o If an individual doesn't seem interested, find another activity for the individual to engage in alone or with another staff member.
o Be beneficial and entertaining for everyone in the group!
  o Avoid picking an activity that is "convenient" for staff members. Select an activity that interests the individuals.
o Activities do not have to be long and time consuming.
  o Fill "waiting" time or periods between transitions with quick activities!
o Be prepared!
  o Always have a list or box of activities as a resource to maintain engagement and fill time.
    o Example: Breakfast is taking longer than expected, not everyone is ready to go on an outing yet.
o Use group activities as a staffing benefit!
  o Example: Moments of being short staffed, multiple staff assisting with an individual or chore.

Avoid the "Waiting" Game

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Name group activities you can arrange while individuals are waiting for meals, transition, or to leave the program.

Individual Engagement

An individual can also be engaged in an activity or item independently.
Individual engagement is shown by the degree of **attention**, **curiosity**, **interest**, **excitement**, or **passion** the individual shows when they are interacting with an item or activity

Describe ways the individuals you work with may independently engage in an activity.
Remember!
Proximity does not equal engagement!

Selecting Items & Activities

- ❖ **Learn the client's likes, dislikes and preferences**
- ❖ **Offer choices**
- ❖ **Ask the client what motivates him/her**
- ❖ **Conduct observations**
- ❖ **Conduct formal preference assessments**

- ❖ **Items & Activities should be:**
- ❖**Age appropriate**
- ❖**Pertain to the person's interest**
- ❖**Easy to maintain supply**
- ❖**Available for access**
- ❖**Ensure the health and well-being of the client**

Questions to Ask

- ✓**Is the activity beneficial for the client?**
- ✓**Does the client have the skills to engage in the activity?**
- ✓**Will it enhance the client's skills and quality of life?**
- ✓**Is it an activity the client desires to learn?**
- ✓**Is it a new activity?**
- ✓**Can the client do any of the activity independently?**
- ✓**Can other individuals engage in the activity as well?**

GOAL

- PROVIDE MEANINGUL AND INTERACTIVE EXPERIENCE
- ENSURE THAT PEOPLE SERVED ARE NOT SIMPLY CUSTODIALLY CARED FOR
- ENSURE THAT STAFF SEE, HEAR, REACH OUT TO, AND ENGAGE THE LEARNER

What is an absence of engagement?

- An absence of treatment
- A failure to provide humane care
- Neglect

ENGAGEMENT IS A PREREQUISITE

- To interaction
- To connection
- To happiness
- To quality of life

Engagement is a right

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- Our clients have a right to meaningful engagement
- We have an obligation to engage

Human Rights

The benefits

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- Reduced behavior problems
- Reduced stereotypy
- Increased social skill training
- Opportunities to incidentally teach
- Creates program excellence

BE THE BEST VERSION OF YOU

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SUPPORTS FOR ENGAGEMENT

- Games
- Magazines
- Manipulatives
- Puzzles
- Computers
- Arts and crafts
- Pads and paper

Another challenge: Orientation

- When disorientation occurs, it may help to embed environmental supports
  - Schedules- weekly, daily, tasks
  - Timers and reminders on phones
  - Labels for items in drawers and closets
  - Checklist at door (do you have…)
  - Put clothing out the night before
  - Pack day bag the evening before

Collaborative Care: Integrating the Expertise of Multiple Discplines

What is collaboration?

- To work, one with another
- To work jointly with others

Synonyms

- Teamwork
- Partnership
- Working together
- Joint effort

We cannot do it alone

Benefits

Good collaborators

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- Willing to try strategies
- Interested in using something new
- Quick to implement suggestions
- High adopters had the most
  - knowledge of curriculum and pedagogy
  - knowledge and student friendly beliefs about managing student behavior
  - student-focused views of instruction
  - ability to carefully reflect on students' learning

(Brownell et. al. 2006)

Components

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- Communication
- Decision making
- Goal setting
- Organization
- Team process

What collaboration requires

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A basic understanding of:
- expertise
- orientation
- terminology
- potential role of the other professionals in the collaborating team

(Geroski, Rodgers and Breen 1997)

Who are the players?

- Medical personnel
  - Nursing
  - Medical doctors
  - Psychiatry
- Ancillary therapies
  - PT
  - OT
  - Speech therapy
- Behavioral staff
  - BCBA
- Program staff
  - Direct care
  - Managerial staff

Why is coordination of care essential?

- Complex problems require multiple perspectives and expertises
- Physical problems will influence behavior
- Aging will bring both physical and behavioral CHANGE

Coordinated care leads to better outcomes

- Adherence with medical recommendations can be enhanced through behavioral contingencies
- Compliance can be enhanced in ways that increase health
- The environment can be modified to increase orientation, engagement, and independence

3/5/2019

Additional resources

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- https://shriver.umassmed.edu/cdder/aging_idd_education/
- https://shriver.umassmed.edu/sites/shriver.umassmed.edu/files/IntrotoAging.pdf

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Questions?

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