



Younger Adults in Skilled Nursing: Ethical Dilemmas and Challenges

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Purpose

- The purpose of this course is to provide a comprehensive overview of the ongoing trend of younger adults moving into skilled nursing centers and the ethical issues and challenges this trend presents.

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Description

- Younger Adults in Skilled Nursing: Ethical Dilemmas and Challenges is a 1-hour continuing education presentation that provides a scoping review of the literature pertaining to this topic.

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- This presentation examines characteristics of younger adults moving into skilled nursing, unique challenges associated with this population and potential ethical problems and solutions for long-term care providers.

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Learning Objectives

1. Describe characteristics of younger adults moving into skilled nursing centers
2. Identify unique challenges associated with this population and some potential solutions

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3. Examine ethical dilemmas and discuss solutions

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Introduction

- There has been a trend in senior care over the last couple decades
- In 2000, younger adults aged 31 to 64 made up 12% of the nursing home population in the U.S.

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- In 2010 the number rose to 14%
- In May of 2022, the National Center for Health Statistics indicated that 16.9% of nursing home residents are under age 65
- This is a sizable majority

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- It's safe to say that long-term care is no longer synonymous with old age or geriatric care

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Why is This Trend Occurring?

- Historically, there has been no where else for younger adults with conditions like traumatic brain injury, HIV/AIDs, serious injuries due to motor vehicle accidents, drug overdoses, hemiplegia, quadriplegia, mental illness and neurodegenerative illnesses

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- More recently, this trend increased significantly following Affordable Care Act Medicaid Expansion, in which Medicaid covers nursing home services of younger people

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- What is unclear is the benefit of post-acute care to this population or if the needs of younger individuals can be adequately met in this setting

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Learning Objective 1

Describe characteristics of younger adults moving into skilled nursing centers

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- We will look at this population in terms of physical, medical, social, psychiatric, substance use or abuse characteristics
- In terms of age, we're looking at 16 to 64 years of age (any age under 65 to 18)

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- They are very different than their older counterparts in skilled nursing in a number of ways, but the clinical conditions they have upon admission make them a unique group

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Clinical Syndromes Upon Admission

- Developmental and intellectual disabilities
- Hemiplegia and quadriplegia due to trauma

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- Much higher rates and severities of psychiatric illnesses and substance-related diagnoses
- Chronic and neurological disorders such as Huntington's disease, muscular dystrophy, ALS, Parkinson's disease, peripheral vascular disease, etc.

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- Many have had previous stays in psychiatric or rehab centers for substance-related conditions
- Any or all of these characteristics require different training and approaches from skilled nursing staff

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- Rates of anxiety and depression, perhaps with suicidal thoughts or actions may be associated with coping with the possibility of living in nursing homes for the next 30, 40 or 50 years of their lives

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- What will this population look like in the next 10-20 years
- How will they receive the care they need?
- How will staff, who are used to working with old adults, feel about this?

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- What will care planning look like?
- Will they require different resident rights? Will they demand more?
- Where will the resources come from for difficult cases and the need for specialists and specialized equipment?

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Snapshot of the Younger Population Already in Skilled Nursing Facilities

- The majority are male whereas they are female in the older resident population
- White people make up the majority of older residents; there are more black and Hispanic in the younger group

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Clinical Characteristics

- Younger people have far more serious mental health issues than their older counterparts (35% compared to 18%)
- Their use of antipsychotic medication is 33% compared to 18% for older residents

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- Cerebral palsy is highest among the 16-19 year olds at almost 34% where it's 0.6% for older residents
- Paralysis is 26% compared to 11% in the older resident population

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- Traumatic brain injury ranges from 4.5% to 15% for younger adults where it's 0.7% for the older residents
- Multiple sclerosis 6% for younger and 1% for older residents

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- Chronic lung between 14% to almost 39% for the younger resident and 24% for the older resident
- Ventilator usage is 35% for 16-19 years olds and 0.3% for older residents

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- Expressive communication impairment is highest among the 16-19 year olds and 40% for older residents
- Dementia is higher among older residents at 53% versus 21.5% for those ages 50-64

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- 50-64 group have diabetes at 42% and the older residents at 34%
- Cancer tends to be slightly higher among older residents at 5.3% and 3.8% for those 50-64

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Nursing Home Locations

- For-profit 82% for younger adults and 69% for seniors
- Urban 95% for 16-19 year olds and 69% for older residents

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- Slightly fewer younger adults live in suburban facilities (13%) and almost 16% for older adults
- More elderly residents (7%) live in rural facilities while 1% to 6% of younger people do

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Younger Residents by State

- Lowest Percentage: Alaska, Vermont and Oregon
- Highest Percentage: Missouri, Ohio, and Illinois
- Majority live in facilities rated 1-star or below

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3 Groups on the Basis of Etiologies of Illnesses and Disabilities

1. Unpredictable fate (chronic, progressive, psychiatric or neurological illness like MS, HD, ALS or schizophrenia they've battled for many years)

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2. Illness and/or institutionalization from birth or childhood (neurodevelopmental disorders like Down Syndrome, Epilepsy, Seizure disorder, intellectual disability, Cerebral Palsy, etc.)

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3. Sudden onset of physical problems related to injury, misfortune or lifestyle (TBI)

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General Themes

1. Confinement
2. Lack of socialization
3. Lack of privacy
4. Lack of appropriate settings to accommodate younger residents
5. Loss of identity

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1. Confinement

- Confined to the building
- Not being included in decisions and placement assignments
- No other options but to live in the nursing home

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2. Lack of Socialization

- With peers (other young residents)
- With wider community
- With family, friends, and significant others
- Age-appropriate activities

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3. Lack of Privacy

- Personal hygiene routines
- Intimacy

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4. Lack of Appropriate Settings to Accommodate Young Residents

- Nursing homes are viewed as old folks homes
- Not a true home but a refuge
- Does not meet their needs

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5. Loss of Identity

- Sense of belonging
- Personhood
- Sense of empowerment

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In Their Own Words

- *This is a place for older adults who are dying and often suffering from dementia*
- *The quality of life is terrible*
- *I feel like I'm talking to my mother all of time*

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- *It's just not normal. I don't fit in.*
- *Everything is timed. When you eat, when you do this or that.*
- *This place makes you feel like a captive*
- *It's hell to live here*
- *Every day is the same old story*

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The Feelings and Experiences of Younger Residents

- Empty landscape of time
- Devoid of meaning
- Boredom
- Loneliness

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- Depression
- Lack of control
- Not sociable enough
- Disconnected
- Unmet needs

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Learning Objective 2

Identify unique challenges associated with this population and some potential solutions

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- This is a challenging exercise since there can be so many problems, issues, dilemmas and conflicts that can arise mixing multiple generations of people together with a wide variety of needs under one roof

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General Categories

- | | |
|----------------|--------------|
| • Clinical | • Financial |
| • Psychosocial | • Staffing |
| • Practical | • Reputation |
| • Regulatory | |

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Clinical Challenges

- Medical directors and nursing staff may not be experienced working with younger residents
- Clinical staff may lack expertise or interest in conditions or diagnoses of younger residents

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- Some conditions like pregnancy and sexually transmitted disease are less common in senior care (but not all!)
- Transition to palliative care and allowing a natural death may be particularly difficult for younger residents, their loved ones and staff

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- Younger residents may have medication regimens that are unfamiliar to staff
- Staff may be unprepared to work with younger people with traumatic brain injury (TBI)

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- They may also be unprepared to work with recently disabled or severely injured younger residents who are just starting to cope with their losses
- Developing a plan or care or care paths may be challenging and many younger residents will want to participate

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- Medication, treatment or care compliance may become major issues
- Staff may be unprepared and untrained in substance use/abuse/addiction
- There may be very medically complex residents with multiple co-occurring conditions

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Psychosocial Challenges

- Variable life experiences based on age, maturity, and greater diversity of needs
- Visitors, friends or family who have little to no experience with health care facilities

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- Sexually inappropriate activity or advances
- Mental, behavioral, or personality issues that are unfamiliar to staff
- Developmental and intellectual disability co-occurring with mental illness

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- Different life stages, expectations, hopes and dreams
- Vices like sex, drugs, rock and roll, crime, theft, leaving for weekends, bringing friends back, etc.
- Aggression or violence towards staff, other residents or property

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- Various sleep-wake cycles and late night activities
- Using social media and technology inappropriately
- Potential visitor problems
- Severity of mental problems

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- Roommates with elderly resident with dementia
- Low literacy rates
- Demanding the right to smoke
- Rule breaking
- Weaker self-management skills

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- More psychosocial needs or demands
- Loneliness, depression, anxiety, suicidality
- Generation tensions
- Lifestyle (music, appearance, friends, habits)

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- Bringing alcohol, cannabis or other substances into the facility
- Low impulse control
- Anger and belligerence to staff
- Resident-to-resident altercations
- LGBTQ+ related issues

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- Non-verbal
- Behavioral disinhibitions
- Polypharmacy
- Personality disorders
- Pain management

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Practical Challenges

- Their age
- Young residents may resent or dislike older people and want to be with people their own age
- Age-appropriate activities

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- Space requirements because younger people will have more stuff like power wheelchairs and computers
- Younger residents are generally stronger
- It is unlikely a therapeutic cluster of like-aged people will form

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- The overall environment just isn't appropriate (although it may certainly be for older residents)
- Will they enjoy the food?
- Will we have enough staff to care for all of their needs?

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- Will staff stay and provide care or find a new place to work with traditionally older residents
- Younger people may have a hard time being around physical decline and death

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- Will younger residents have patience with dementia-based behaviors?
- What will their quality of life be in physical, mental, emotional, spiritual and personal growth areas of their lives?
- Will they want to be a part of the outside community more than elderly residents?

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- How will they react to stigma, discrimination or stereotypes from staff or older residents?
- Where are the regulations and guidelines for providing care to younger residents?

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Regulatory Challenges and F-Tags to Be Aware Of

- As of now, federal and state regulations are not designed for younger individuals in skilled care
- MDS screening and assessments are not validated for younger residents

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- There will be challenges in developing new policies and procedures that are regulation-friendly to address younger residents' needs while maintaining safety

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F-Tags

- F151 – Exercise Rights/Vote/Free of Coercion
- F152 – Resident Competency
- F154 – Informed of Health Status/Medical Condition
- F155 – Right to Refuse Treatment/Research
- F156 – Inform of Services/Charges/Legal Rights

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- F157 – Notify of Accidents/Significant Changes/Transfers
- F164 – Privacy and Confidentiality
- F165 – Voice Grievances without Reprisal
- F166 Facility Resolves Resident Grievances
- F172 – Access and Visitation
- F176 – Self-Administration of Drugs

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- F223 – Abuse
- F224 – Staff Treatment of Residents
- F240 – Facility Promotes/Enhances Quality of Life
- F241 – Dignity
- F242 – Self-Determination/Resident Makes Choices

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- F244 – Facility Listens and Responds to Resident and Family Groups
- F245 – Resident Participates in Activities
- F246 – Accommodation of Needs and Preferences
- F248 – Activity Programs Meets Individual Needs

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- F252 – Safe/Clean/Comfortable/Homelike Environment
- F280 – Development/Preparation/Review of Comprehensive Care Plans
- F309 – Necessary Care for Highest Practical Well-Being
- F311 – Resident Treatment to Improve/Maintain ADLs

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- F314 – Treatment to Prevent Pressure Injuries
- F323 – Facility Free of Accidents and Hazards
- F325 – Maintain Nutritional Status
- F329 – Free from Unnecessary Drugs
- F500 – Use of Outside Professional Resources

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Financial Challenges

- There will, most times, be money issues
- Financial risk for litigation may be higher due to risky behaviors
- Few younger adults will have Medicare
- Insurances may not cover specialty treatments

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- Younger residents may require greater physical care but be intact cognitively, and therefore make more financial demands and have more preferences that can be resource-intensive and expensive

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- Reimbursement issue may pose problems (holding a bed for a long time for a resident who has high demands and low reimbursement)

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Staffing Challenges

- Staff may not want to work with this population
- Some will stay and have to change their mindset
- Boundaries and boundary violations can become an issue

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- Younger residents may intrude into the lives of staff
- Aggressive and highly mobile residents can create safety issues for staff
- Power wheelchairs can do damage to flooring and require extra maintenance

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- Heavy physical care can lead to staff injuries
- Younger residents may know how to manipulate staff and push their buttons, causing chaos and conflict

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Reputation Challenges

- Younger residents might scare older residents
- They may simply not mix well and the conflict can spill out into the community

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- Incidents may occur which grabs the attention of local media, law enforcement, etc.
- Younger residents might hang out in the front of the facility, reducing curb appeal
- It might be difficult to discharge a problem resident because they tend to know their rights

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Potential Solutions to Unique Challenges

- Person-centered care cannot be more important for younger residents
- Identify their individual perspectives that inform their unique needs and wants

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- Make it well known that staff will respect their privacy
- Reimagine the activity department and gear age-specific groups and social activities towards this population

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- From the start, establish appropriate and healthy relationships between residents and staff
- Take time each day to take time, visit and listen to their needs
- Create a therapeutic milieu

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- Anticipate cognitive problems
- Create behavior management policies and procedures the staff will know and deliver in practical ways
- Establish creative balances between health, rights and safety

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- Develop policies and procedures for time out of the facility, smoking, power wheelchairs, etc.
- Train staff on all issues associated with younger residents
- Celebrate success

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- Contract with reliable and successful psychiatric teams
- Get early mental health referrals
- Develop peer-to-peer support programs or find them in the community

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- Host Alcoholics Anonymous, Nicotine Anonymous and other groups for younger residents to attend
- Develop a computer lab or space within the building

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- Establish effective communication between departments, shifts, consultants, etc.
- Hire nurses and/or social workers with psychiatric/psychological experience

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- Do not waiver on the need for certain types of medications for this population, and in particular, psychotropic medications
- Help younger residents work through loss in healthy ways

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Behavior Manage Planning & Implementation

- Identify behaviors you want to eliminate and those you want to reinforce
- Create specific and measurable goals that are time limited

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- Select rewards for successfully completing short- and long-term goals
- Select consequences but not punishments
- Choose a time for evaluation
- Sign and date a contract

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Things to Remember

- They are sick
- They haven't chosen this way
- They are suffering
- Look for unmet needs
- Maintain boundaries

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- Try something and if it doesn't work, try something else
- Disengage if or when you have strong emotions
- Watch your tone when speaking and documenting
- Be empathetic

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Activities for Younger Residents

- Get them out as much as possible
- Community walks to local stores
- Laundromats
- County fairs
- Attending schools

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- Music, choirs, drum circles
- Book clubs
- Movie nights
- Spiritual, religious
- AA, OA, NA meetings
- Blog
- Do something for a charity
- Internet café
- Contests and tournaments
- Gardening

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- Nature trips
- Holiday decorating
- Local high school sporting events
- Follow NFL, MLB, NBA
- Dress-up activities
- Wheelchair races
- Fine arts
- Create cards to send
- Happy hours with mocktails

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- Mentor new residents
- Become an ambassador
- Men's and women's clubs
- Outside speakers
- Cooking programs
- Monthly resident choice meals
- Pets
- Gaming

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Learning Objective 3

Examine ethical dilemmas and discuss solutions

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- This part of the presentation could go on for a very long time
- We've covered so many ethical issues and problems already, but there are more to address

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- Should they even live in a skilled facility?
- Can their needs really be met?
- Can we deliver true person-centered care?
- Is it safe?

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- Who's equipped and experienced with severe mental illnesses?
- Is it fair for the young adult, other residents, family members and staff?
- Might they become a resource and time drain for the staff and building?

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- Will they feel trapped, deprived and alone?
- Will they be bored and looking for things to do with vast amounts of time?
- What types of boundaries violations will occur?

104



- Will we see stigma, discrimination, stereotyping and prejudice?
- How will we balance rights with responsibilities?
- How can we create meaning and purpose in their lives?

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- What about respect for autonomy?
- Beneficence?
- Nonmaleficence?
- Justice?
- Decision-making?
- Harm to others and self?
- Confidentiality?
- Access to care?

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Some Solutions

- Train staff well
- Establish policies and procedures
- Open up communication between all departments
- Hire nurses, social workers, etc. with psychiatric or behavioral experience

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- Create multiple therapeutic programs
- Keep a happy and positive atmosphere
- Get the best contracted consultants in mental and behavioral health with young people

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- Young resident council
- Peer-to-peer support
- Distinct recreational activities
- Develop trusting and genuine staff-resident relationships
- Develop create care plans

109



- Crank up rehab services
- Learn about best practices in brain injury, developmental disorders, substance use and severe mental illness
- Help them plan for the future and find more appropriate housing

110



- Throw an SOS out to your community of professionals and services and don't be afraid to ask for their advice and help

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Thank You and Stay In Touch!

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